

**SURVIVING THE DEATH OF A BABY: END OF LIFE
AND THE ENORMITY OF GRIEF**

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Glossary of terms

Bereavement nurse – A named nurse who supports the family on the phone and by visits after the death. Time frames for support vary

Edwards syndrome – Also known as Trisomy 18, where all or part of an extra copy of the 18th chromosome is present causing a range of severe problems. Most babies die at birth or shortly after.

End of life care – a part of palliative care that encompasses the last days of a baby's life, care during and after death of the baby and family.

Gestational age – The number of weeks and days the baby is in the uterus. Corrected gestation is the age in weeks and days post-premature birth.

Intra-partum haemorrhage – a maternal haemorrhage occurring during the course of labour or delivery.

Neonate – a baby in the first 28 days of life. However, babies stay on a neonatal unit beyond that time frame.

Palliative care – an active and total approach to care from diagnosis, through the baby's life, death and beyond. It involves physical, emotional, social and spiritual care of the baby and family.

Premature birth – a baby born before 37 weeks gestation.

Small for gestational age – weight below the 10th percentile for their gestational age

Term birth – a baby born at 37 weeks gestation or more.

Withdrawal of treatment – a withdrawal of a baby's life-sustaining treatment, agreed with the parents and multi-disciplinary team, comfort and nursing care continues.

Abbreviations

ACP – Advance care plan, a voluntary plan for a patient's wishes and preferences as their condition deteriorates, reaching end of life and after death.

CRP – C-reactive protein, a common blood test to measure inflammation levels in the body.

CPAP – Continuous positive airway pressure, a less invasive mode of respiratory support than a ventilator.

DNACPR – Do not attempt cardio-pulmonary resuscitation

HIE – Hypoxic ischaemic encephalopathy, a type of brain injury and resulting damage that occurs due to a lack of oxygen to a baby's brain.

IPA – Interpretative phenomenological analysis

MRSA – Methicillin resistant staphylococcus aureas, bacteria resistant to widely used antibiotics.

NEC – Necrotising enterocolitis, a disease of the neonatal bowel, prevalent in premature babies where the bowel becomes inflamed and tissue can die.

NGS – Neonatal Grief Sandstorm

PTSD – Post traumatic stress disorder, an anxiety disorder caused by stressful or distressing events.

SANDS – Stillbirth and neonatal death society

SDLD – Surfactant deficient lung disease – a common lung disease in premature babies.

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*"Give sorrow words;
the grief that does not speak,
Whispers the o'er-fraught heart and bids it break."*

(Shakespeare, Macbeth, Act IV, Scene 3)

Michaela Barnard

Abstract - Surviving the death of a baby: end of life and the enormity of grief

Aim

To explore parents' experiences and perceptions of support during and following the death of their baby.

Study design

An interpretative phenomenological approach was adopted with in-depth unstructured interviews undertaken with seven participants whose baby had died in a north west neonatal intensive care unit. The study was conducted in a way that was sensitive and respectful to undertaking research with bereaved parents. Data were analysed using interpretative phenomenological analysis to describe and interpret parental experiences.

Findings

Four superordinate themes emerged from the data analysis: 'the enormity of grief', 'being isolated', 'trying to survive' and 'routes to an improved future'. Parents' grief experiences were at times insurmountable and they perceived that their grief was not always understood by family and friends, and that health professional support was variable. The 'Neonatal Grief Sandstorm' visual tool is offered as a way for both professionals and bereaved parents to visualise and discuss common experiences of bereaved parents.

Outcomes

This thesis has represented the voices of parents and their perspective following neonatal bereavement. This appears to be the first study in the world to link neonatal end of life care to parents' grief experiences, and the first use of interpretative phenomenological analysis to facilitate the parent's voice on experiences of and life after a neonatal death. The study provides insight into mothers' and fathers' grief experiences after the death of a baby in a neonatal unit. A novel finding was the significance of obstacles to high quality neonatal end of life care and the negative effect that this had on perceived quality of care and grief experiences. The Neonatal Grief Sandstorm is the first visual tool of its kind in neonatal palliative, end of life and bereavement care.

Chapter 1 - Background and context

1.1 Introduction

While the medical and technological advances in neonatal care have improved the survival of premature babies, not all will survive past the neonatal period. As neonatal care has developed, policy about the commissioning and way services for neonates are delivery have been published (Department of Health [DH], 2008a), along with benchmarks for standard of care (BLISS, 2009; National Bereavement Care Pathway, 2018). Central to neonatal care are the support needs of the family, particularly in preparation for discharge with recognition that for many families, their baby will have ongoing care needs but there has been less focus on parents whose baby has died. This in part may be due to lack of understanding of what it is like for parents who have experienced the death of a baby being cared for on a neonatal unit. This doctoral study focused on the experiences and support needs of parents whose baby had died on a neonatal unit or intensive care unit during the neonatal stage of life. This chapter will present and discuss rationale for the study and current organisation of neonatal care in the UK. The theoretical perspectives of grief, mourning and attachment will be discussed and analysed. First, my relationship to this care setting and the concept of anticipatory grief will be outlined.

1.2 The researcher

Interest in the support needs of bereaved parents following a neonatal death stems from a fifteen-year career working as a neonatal nurse in neonatal intensive care unit (NICU). For seven years, I worked as a bereavement support sister in a tertiary NICU, offering a range of support strategies to families at the time of death and in the community after the death of their baby. This role incorporated developing guidelines for palliative, end of life and bereavement care. While developing evidence-based care plans and guidelines, it was evident that there was a lack of empirical research in neonatal end of life bereavement care in the United Kingdom (UK). The desire to know more about parents' perceptions of their grief journey and what support would be useful has been influential throughout the stages of undertaking this thesis.

I felt it was important to acknowledge my position within the research as a bereavement nurse, a researcher but also as a mother who has experienced anticipatory grief related to foetal abnormality. It has been essential to identify my own experiences of grief in a similar care setting and acknowledge what, if any, impact this might have on my doctoral study. In 2006, when I was 20 weeks pregnant, my baby was diagnosed with Trisomy 18, Edwards Syndrome, which has a life-limiting prognosis, and it is normally considered 'incompatible with life'. I fully expected my baby to die after birth. From this point onwards in my pregnancy, I experienced anticipatory grief, living with uncertainty and a range of emotions. I continued to work in the neonatal intensive care unit setting for the next four months. At birth, my baby was healthy, and the diagnosis had been made in error. However, I continued to work through the emotions from this grief journey for the next year, and perhaps beyond.

When I entered my own grief journey, I was already working as a bereavement support nurse, and continued to support bereaved parents after returning from maternity leave for 4 years after this experience. Although this personal event had significant impact, it was not the motivation for my interest in this field of care or research. However, as the study design adopted for this thesis was a qualitative phenomenological approach, acknowledging my personal grief journey was important as these experiences influence my perceptions of grief. Additionally, my experiences afforded some insights into the possible emotions, feelings and experiences that parents in my study might encounter but with active awareness that my pattern of grief was wholly individual as were the grief patterns of participants in this study.

Throughout this study, I kept a reflective journal of events, experiences and feelings. This is in keeping with a qualitative methodological approach, and in particular phenomenology, but regardless of approach, journaling is essential in a study that is sensitive in nature. Ongoing reflection, alongside clinical supervision from an independent individual, was essential because bereavement research carries a psychological and emotional burden, which requires anticipation from the beginning of the study through to the end point. From data collection onwards, I had regular clinical supervision appointments with a counsellor experienced in engaging with bereaved adults, with the aim of promoting and maintaining my own emotional health and wellbeing. Personal reflection boxes will be used throughout this thesis as a way

of documenting my thoughts and feelings, and where appropriate initial interpretations of the data, without interrupting the flow of information being presented.

Alongside reflection, reflexivity was central to my development as a researcher and in ensuring assumptions, values and experiences that had the potential to impact on the research processes and findings were accounted for. Reflexivity has been described as the influence of the position, perspective and presence of the researcher on the research itself, as the researcher is the pivotal individual that influences how the research is accomplished (Bradbury-Jones, 2007; Finlay, 2002). Therefore, reflexivity is inexplicably linked with credibility because the actions and decision-making of the researcher influences how meaning from the data is constructed and the how the research process is managed (discussed further in Chapter 5, Section 5.4).

Clinical expertise in neonatal palliative and bereavement care meant that my knowledge was positioned from a perspective of experience and some insight into grief theory and the contemporary evidence-base for care. Prior to this study, I presumed to understand aspects of parents' experiences of end of life from the care and conversations I had engaged in NICU and bereavement visits. However, this knowledge was anecdotal in nature and it lacked a holistic understanding of end of life experiences and how they linked to grief.

During early supervision, my thinking was challenged alongside emerging themes from the literature, opening up fresh perspectives and a focused direction for the research. For example, I had initially intended to explore the support experiences only, but it became apparent that there was a need to describe, understand and interpret end of life experiences through the parental lens alongside support experiences. Developing the skill of reflexivity was influenced by the patient and public involvement group (PPI), the data from the participants themselves, academic supervision and clinical supervision. As the research progressed, academic supervision challenged my preconceptions and decision-making with monthly meetings facilitating critical thinking and reflexivity. Further, the clinical supervision aimed at promoting health and wellbeing also contributed to examining my own position in the research. Through monthly clinical supervision, I developed

heightened self-awareness of my own values and experiences on the research process.

A reflexive account is woven throughout this thesis using both the reflection boxes and general discussion to allow scrutiny into the integrity of the research process. This account provides insight into critical thinking, personal responses to situations that were encountered and any arising outcomes.

1.3 Rationale for the study

Every year an estimated 4 million babies die globally before the age of 4 weeks; the main causative factor for these deaths in developed and developing countries is preterm birth (Lawn et al, 2005). One in every 150 babies born in the UK is stillborn or dies immediately after birth (Mothers and Babies Reducing Risk through Audits and Confidential Enquiries [MBRACE-UK], 2015). The UK neonatal mortality rate (death under 28 days of life) was last reported at 2.8 per thousand live births, and in 2012 approximately 2,200 babies died in the neonatal period (Office for National Statistics [ONS], 2014). Babies on a neonatal unit can be categorized by their gestational age and weight, presented in Table 1.1 (World Health Organization [WHO], 2015). Babies located in the extreme prematurity and extremely low birth weight categories have higher mortality rates (ONS, 2014). Advances in medical and pharmacological technology have facilitated developments in care and treatment for both neonates on the edge of viability (23-24 weeks gestation) but also sick babies up to term gestation. However, these advances in technology, pharmacology and treatment do not ensure that all babies will survive past the neonatal period. The ability to sustain life at the edge of viability or when a baby is extremely sick can mean that while resuscitation and early stabilisation is often possible, complications of prematurity, care and treatment mean that death may be unpreventable (Barnard and Weaver-Lowe, 2016).

Table 1.1 Categories of prematurity

Gestation		Weight	
Preterm	<37 weeks	Low birth weight	<2500g
Moderately preterm	35-37 weeks	Very low birth weight	<1500g
Very preterm	29-34 weeks	Extremely low birth weight	<1000g
Extremely preterm	24-29 weeks		

Neonatal units in the UK are categorised into three levels of care provision (DH, 2009). Special care units (SCU) provide neonatal care for local populations, which may include some high dependency care and stabilisation for transfer to a unit that provides a more intensive level of care. Local neonatal units (LNU) provide neonatal care for local populations unless the baby is very premature (<27 weeks gestation) and/or very sick. Neonatal intensive care units (NICU) are located alongside other specialist services such as specialist foetal and obstetric services. These units provide the full range of neonatal care for their local populations and for any very premature, sick babies or babies requiring surgery from across the neonatal network (DH, 2009). There are 16 neonatal networks, also referred to as operational delivery network (ODN), across the UK. These networks were designated by the DH to ensure that babies and families across each region would receive high quality care that is equitable across the UK (DH, 2009).

The commissioning of neonatal services includes the provision of high-quality palliative and end of life care for babies and their families. Meeting the physical, psychological and social needs of families should be at the centre of end of life care. End of life care does not conclude at death but extends into the initial period of bereavement. Yet evidence suggests that many families experiencing bereavement following the death of their baby are not offered formal psychological support (Robertson et al, 2011). Hospitals with resourced bereavement care have largely based their strategies on experiential success of more established bereavement teams within the wider field of children's nursing. These teams often use audit to gain insight into the effectiveness of their support and seek parental opinion on success and development. A robust evidence base for neonatal end of life and bereavement support has the potential to advance care and support in this specialised field. Imperative to the evidence in this field is the parental voice (both mothers and

fathers), informing future care and service development from their own experiential journey.

In the context of palliative and end of life care, the bereaved family has multiple and ongoing practical and psychological care needs, and these needs should be incorporated into end of life care guidelines (DH, 2008a p. 34; ACT, 2009; National Institute for Health and Care Excellence [NICE], 2016). While some of these national guidance documents are over 10 years old and require updating they are still used to inform the way neonate care is delivered. Policies such as the Toolkit for High Quality Neonatal Services (DH, 2009) and Better Care, Better Lives (DH, 2008a) guide both the commissioning of care and policy development for neonates and their families at the end of life (DH, 2008a and DH, 2009). Yet, little guidance is provided within these policy documents about family support following neonatal bereavement or the structure and resources required to develop bereavement support teams. The transition from a NICU to home after the death of their baby can leave families feeling abandoned (D'Agostino, Berlin-Romalis, Jovcevska, Barrera, 2008). Published standards of care for babies on a neonatal unit from the third sector specifically describe a benchmark standard of care (Standard 2.5) for babies and their families at the end of life (BLISS, 2009). BLISS is a UK charity that works with families and health professionals to ensure that sick babies have the highest quality care possible. All parents, who have their baby admitted to an NICU in the UK are introduced to BLISS through welcome packs. Consequently, families may have an expectation of receiving supportive and sensitive end of life and bereavement care from a multidisciplinary team that works in partnership with parents in order to meet their needs (Price et al, 2012).

The number of neonatal deaths each year varies considerably across neonatal units according to their dependency designation and bed capacity (DH, 2009). NICUs experience greater numbers of deaths per year compared to LNUs and SCUs because they care for the sickest infants, with complex needs and those with extreme prematurity. Consequently, health professionals experience of dealing with palliative, end of life and bereavement care will be variable: professionals on NICUs are the most likely to have cared for babies who have died, with those on LNUs likely to have the least experience. Nevertheless, LNUs and SCUs should be able to

provide good quality palliative care, and babies may be transferred back to a local unit for this care provision. How much, if any, support is offered to families after the death of a baby ranges from end of life care with no support after the death, to a bereavement team including support nurses and access to a bereavement counsellor. Better support services appear more likely, but not exclusively, to be available in the NICUs (Robertson et al, 2011). The provision of a follow-up appointment with the baby's consultant, normally 6-8 weeks after the bereavement seems to be the only standard intervention across UK units (Robertson et al, 2011). There is inequality in relation to neonatal bereavement care within the UK, often dependent on the geographical location of the unit and the level of care provided at the unit where the baby died. Where inequality of care exists, bereaved parents' support needs are unlikely to be met.

1.4 Defining bereavement, grief and mourning

Offering definitions of bereavement, grief and mourning and the key terms that will be used throughout the thesis will assist with the interpretation of parents' descriptions and experiences. In addition, defining terms will also aid critical evaluation of the theories and models outlined later in this chapter. The terms bereavement, grief and mourning are often used interchangeably both in everyday conversations and in clinical practice. However, their differences are significant and outlining these differences may help contextualise the study findings. Bereavement is commonly understood to be the death event. Kastenbaum (2012) described bereavement as "an objective fact" (p. 350), whereas Stroebe, Stroebe & Hansson (1993) offer a definition of bereavement as "the objective situation of having lost someone significant" (p.5). The concept of bereavement has been explored and analysed in the perinatal stage of life encompassing both the in-utero and neonatal stages (Fenstermacher and Hupcey, 2013). Advancing the concept of perinatal bereavement provides additional clarity, specifically giving up a baby for adoption, birth of a baby with abnormalities or a disappointing birth experience are not included within the concept of perinatal bereavement (Fenstermacher and Hupcey, 2013). The findings from this concept analysis suggest perinatal bereavement should be considered as the wider experience of bereavement, grief and mourning due to death of a baby (Fenstermacher and Hupcey, 2013). However, for the purpose of this thesis bereavement will be defined as the objective death event only (Kastenbaum,

2012; Stroebe et al, 1993). This is to ensure that the terms used within the thesis explicitly define the nature of the event and experience that parents describe.

Grief is a multifaceted and complex concept, which is difficult to define (Kastenbaum, 2012). One of the most influential and controversial viewpoints of grief was postulated by Engel (1961) who posed the question of whether grief is a disease. He argued that grief was a disease state with an anticipated progression and identifiable, known symptoms (Engel, 1961). Engel's argument has been interpreted both literally that grief is a disease, and more broadly suggesting that health professionals should widen their concept of disease to include non-physical patterns of behaviour (Stroebe, 2015). Later definitions of grief are more consistent in terms of defining the experience of grief as being a response to the bereavement; it is the physical and emotional hurt arising when a love tie is severed through death (Parkes, and Prigerson, 2010). Grief has been described as "how the survivor feels. It is also how the survivor thinks, eats, sleeps and makes it through the day" (Kastenbaum, 2012, p. 350). Stroebe et al (1993) describe grief as "the emotional response to one's loss" (p.5), however, it can be argued that grief is more than a purely emotional response. These descriptions highlight that grief impacts on all aspects of one's self, sometimes consuming the whole person. Grief has been described as the personal experience of the loss, whereas mourning is the process through which an individual journeys (Worden, 2009). For the purpose of this thesis, the definition of grief that will be used is a physical and emotional hurt arising when a love-tie is severed through death (Parkes and Prigerson, 2010).

Mourning refers to the process through which an individual journeys and Kastenbaum (2012) describes it as "the culturally patterned expression of the bereaved person's thoughts and feelings" (p. 353). Klein (1940) described the mourner as being ill and Engel's initial position of grief echoes this description by Klein where these experiences indicate ill health and disease. However, Engel considered mourning to be different, he suggested it is a move towards and similar to healing (Engel, 1961). There is clear ambiguity of terminology amongst those investigating the phenomenon of mourning. For the purpose of this thesis, mourning will be defined according to the more recent theory by Worden, as the process that occurs after loss, not the experience (Worden, 2009). The three terms bereavement, grief and mourning are inexplicably linked to the way the death of a loved one is

enacted. Although subtle, understanding the differences between terms is essential to understanding the theories presented in the next section and when explaining the study findings.

1.5 Theoretical perspectives

The following section presents a critical analysis of theoretical perspectives in order to understand the experiences of parents' grief. First, the concept of attachment is explored, drawing on the work of Bowlby (1997), Ainsworth (1979) and Rubin (1976). An overview of theories of grief and loss are presented, examining 'normal grief' in detail. Second, the concepts of complicated, anticipatory and disenfranchised grief are discussed. Finally, the theoretical perspectives that guided the findings of this thesis are considered.

1.5.1 The importance of human attachments

To understand the processes of grief that an individual might experience, considering how and why humans make attachments and their value and importance to the individual is a useful starting point; one of the most enduring and power human attachment is the one that evolves that between a mother and baby. Human attachments have been widely studied because of their impact on child development, relationships and security in multiple contexts (Freud, 1939; Bowlby, 1997). Comprehension of the meaning and value of human attachments offers insights into the impact on an individual's grief process.

The need for human beings to have children, care for and protect them to ensure their survival, is arguably instinctive (Bowlby, 1997). A range of hypotheses have been offered to explain a mother's instinct to care and attach to offspring, and all mammals appear to have a complex system of neurotransmitters and hormones that affect, initiate and regulate social bonding with offspring (Eisler and Levine, 2002). Lorenz is credited as the pioneer of early research exploring attachment in animals and developed the concept of imprinting. This seminal study is not available in an English translation, however a review of Lorenz' research that explored imprinting in the bird kingdom and the instinctive response of a mother bird was undertaken by Bowlby (1997). Lorenz found that the more immature the chick was at hatching, the simpler the instinctive attachment response was by the mother. Further, these findings suggested that attachment can only occur in a critical time window, it is

irreversible, and it influences future behaviour (Bowlby, 1997). Lorenz vehemently asserted that imprinting does not extend from the bird kingdom into mammals, however Bowlby argued against that assertion (Bowlby, 1997). Humans, particularly women, have a powerful drive to reproduce. Once a baby is born, there is an intense need to form a relationship with the baby to ensure its safety but also to fulfil the human need to love and be loved (Bowlby, 1997). When babies are born prematurely, it is likely as in Lorenz's bird studies, that there is a more instinctive attachment drive in the parent. The human desire for a lasting parental bond with their child is normally inherent and automatic. However, some parents experience difficulty developing this bond, for a range of reasons such as problems with their own attachment to their parents, abuse in childhood, unfavourable news in pregnancy, and giving birth to children with sensory impairments (Oshri, Sutton, Clay-Warner, Miller, 2015).

Bowlby's (1997) attachment theory provides a way to conceptualise how humans form attachments. Bowlby (1997) suggested that attachment behaviours are a reciprocal arrangement between mother and young, where both parties have a role to play to ensure secure attachment. Bowlby's concepts of attachment were further developed by his colleagues Ainsworth, Blehar, Waters, Wall (1978) who explored the influence of patterns of interaction between the infant and mother. The key findings included that early attachment and bonding can have a significant effect on the strength and security of future interaction and relationships. Behaviours such as touching, looking, smiling, approaching, clinging and crying have all been used to assess the strength of attachments between mother and infant (Bowlby, 1997; Ainsworth et al, 1978; Sroufe and Waters, 1977). These modes of attachments have been theorised into adult attachment styles, with observation of different behaviours, and they have consequently been categorised as secure, avoidant and resistant attachments (Ainsworth et al, 1978; Hazan and Shaver, 1987).

Bowlby's attachment theory has frequently been criticised. Bowlby's suggestion that attachment is based solely in nature and not in nurture has been challenged. More contemporary study suggests that social settings can be designed to support and develop attachment and caring responses in the brain (Eisler and Levine, 2002). Further, the momentary events such as an infant's separation from its mother is not always as significant as first proposed by Bowlby (Harris, 1998; Field, 1996; Bowlby,

1997). While it has been postulated that attachment is prompted by nature rather than nurture, it is suggested that emphasis should not be placed wholly on the mother as the sole attachment figure (Field, 1996). Further, Field (1996) suggested that rather than focusing on stressful situations such as separation and reunion to assess mother-infant attachment, mothers and infants' mutual interactions should be observed in a familiar environment.

Most theories on human attachment focus only the mother's role and not the father's role (Bowlby 1997; Freud 1939, Bretherton, 1992). This, in part, may be due to early studies, which were undertaken with mammals and focused on the mother's role in caring for young in the animal kingdom. Further, in the era in which many of these theories were developed (early to mid-1900s), fathers had a less active role in parenting and opportunities to form attachment, compared to contemporary society. In most contemporary western cultures, the father's attachment and role in parenting has greater recognition and is facilitated and valued. The impact of a father's developing attachment with their child has been brought together in a meta-analysis of three decades of research on father-child attachment, which found that children make as secure attachments to fathers as to mothers (Lucassen, Ljzendoorn, Volling, Tharner, Bakermans-Kranenburg, Verhulst, Lambregtse-Van den Berg, Tiemeier (2011). Fathers also have capacity for a similar sensitivity to their child as do mothers (Lucassen et al, 2011). It is logical to surmise that if the strength of fathers' attachments to their baby can be similar to mothers', then fathers' experiences of a neonatal bereavement may be of similar intensity to that of mothers.

Attachment and loss are intrinsically linked, and Bowlby identified that when an infant experiences loss through death of the figure to whom they were attached grief can be short-lived but yearning occurs over a longer but undefined period of time (Bowlby, 1998). While Freud's work is reinforced by some of Bowlby's conceptual thinking, in that mourning and loss are prominent in his theorising, Freud also emphasised that only on rare occasions does a single event of loss have a significant, long-lasting impact on a child in the early years (Freud, 1939). However, child experiences are likely to be different to adults because of different stage of cognitive development and life experiences; in relation to this study parents will have different perceptions and experiences of attachment, alongside expectations of longevity of attachment compared to studies with children. The seminal theories on human attachment

discussed previously, originate from the perspective of the child's attachment to the mother: that is, the importance of the presence of the mother to the child's psyche (Bowlby, 1997). However, this thesis is a report of the reversal of this powerful drive, the importance of the presence of the child on the parents' need to attach, and the consequences when that is not possible or is lost.

The purpose of this thesis was to explore bereaved parents' experiences of the death of their baby and identify their support needs. Examining human attachment in pregnancy and the behaviour and action of parents to develop a powerful attachment to their unborn child may help to understand the loss experienced following the death of their baby. Rubin (1976) conceptualised four interdependent tasks in the process of maternal attachment in pregnancy and after the birth. Two of the tasks were concerned with the external world. First, safe passage of the mother and child through pregnancy, labour and delivery; and, second, ensuring acceptance of the child into the world by the mother's spouse, other children and family. The other two tasks focused on the mother and her relationship with the child, namely 'binding-in' with the child, and learning to give of herself. 'Binding-in' refers to the bonding process that needs to occur between mother and child in order to facilitate the emotional connection. This emotional connection influences the eventual realisation of physical dependency, through which the mother can fully realise the true dependency of the infant on her care-taking. The mother then attends to the fourth task 'learning to give of herself' which Rubin (1976) describes as the ability to accept a lack of control over mothering tasks related to the unpredictability of a baby. The 'binding-in' process begins in the second trimester of pregnancy when the mother develops an awareness of foetal movements and this binding-in continues throughout the third trimester (Rubin, 1976). Therefore, mothers have already established an attachment with their baby before birth; seeing and holding their baby will strengthen and solidify this attachment.

It can be argued that fathers do not experience the same level of attachment in the antenatal period, because of the lack of tangible presence of the baby in their physicality and lives. However, fathers that are involved in antenatal appointments and are present at ultrasound scans have tangible experiences that enable them to establish antenatal attachments with their baby (Condon, Corkindale, Boyce and Gamble, 2013). Research using quantitative questionnaires in a longitudinal study of

311 first-time fathers in Australia exploring father-to-infant antenatal and postnatal attachment, found that pregnancy is a significant time for creation of the father-infant bond (Condon et al, 2013). Therefore, exploring fathers' views about family life and becoming a father, or in the case of this study the death of their baby, can help to understand and identify their experiences and support needs.

When a baby dies, parental attachment to the baby is of short duration compared with other parents whose babies survive, however the strength of this attachment can be significantly underestimated. It has been suggested that the power of attachment even when for a brief time period is strong and powerful, with little difference between the bond of a mother and deceased newborn and the bond between a widow and deceased spouse (Bowlby, 1998). Bowlby suggested that there was a difference in the affectional bond between these groups of grieving individuals in that widowed spouses had a great sense of loneliness whereas bereaved parents did not necessarily have this experience. Those working and researching with bereaved parents have challenged this concept. Parents in a marriage or partnership who have experienced child bereavement can also experience loneliness (Kavanaugh and Herschberger, 2007). They may be living with a partner or other children but can find it difficult to ask for support and or offer support to other family members (Riches and Dawson, 2000). Therefore, a lack of longevity of attachment is not necessarily proportionate to the impact of grief on an individual. Similarly, living with or having contact with others in the family who are going through the same experience does not necessarily result in a shared support network that lessens the impact of grief.

Parents' ability to make an attachment with their babies will be influenced by their own attachment experiences in childhood. Research suggests that the security and stability of attachment in childhood has an impact on the ability to form attachments throughout childhood and adulthood (Pickover, 2002). Internal factors that contribute to developing attachments are the quality of parental or in loco-parentis attachment, physical and emotional inadequacies of the child's living conditions, and the consistency of quality of care from significant carers (Thompson, 2000). External factors can impact on a parent's ability to attach to their baby. In the context of this thesis, external factors include the receipt of difficult news in pregnancy such as the baby having a life-limiting diagnosis, premature birth, or the need for care in a NICU, the impact of which is an interruption in their parenting role (Côté-Arsenault and

Denney-Koelsch, 2011). Other factors that influence parental attachment are a previous death of babies or children, and the loss of one baby in multiple pregnancies (Pector, 2004). Clinical environments such as NICU create physical barriers that impede attachment and physical touch between the parent and baby, for example, an incubator and life support machinery. Most parents in this situation will not have held their baby after birth, and many do not see their baby until hours after birth because of the intensive interventions required to stabilise their baby. When a baby dies in a NICU, parents may not have held their baby until after death; therefore, the initial period for developing an immediate attachment is denied.

The experience of attachment in the neonatal period is an individual one for both mothers and fathers, however attachment theories can assist health professionals in understanding some of the conscious and sub-conscious bonding processes that parents encounter. The premature severing of an attachment to a beloved baby through death is a significant experience, however the impact of this event on individual parents' lives can vary. Grief and mourning theories, alongside attachment theories, need to be understood by health professionals to be able to empathise and care for parents sensitively in these difficult situations.

1.5.2 Overview of uncomplicated grief

Grief is a unique experience to the individual and their situation. The ability to understand common theories of grief is helpful to understand how people react to death, and how best to support the individual through their grief journey. This section will provide an overview of grief theories starting with what are referred to as the 'normal grief processes' before considering complicated or pathological grief, disenfranchised grief and anticipatory grief experiences.

'Normal' grief processes (also referred to as uncomplicated grief) have been theorised by several researchers (Freud, 1954; Kubler-Ross, 1969; Parkes and Prigerson, 2010; Worden 2009; Klass, Silverman & Nickman, 1996; Strobe and Schut, 1999). These theories describe the common emotions and behaviours experienced by those grieving, however they are each conceptualised slightly differently. For example, grief and mourning have been theorised as a linear process, with an end point of restoration or resolution (Freud, 1954; Kubler-Ross, 1969). In contrast, other theories conceptualise grief and mourning as a forward journey with

'moving on' as an end point, where grief and mourning is a process of moving back and forth between differing emotions and closure may not occur or be desired (Klass et al, 1996; Stroebe and Schut, 1999). However, factors including lifespan development, the nature of human attachment, predisposing factors such as vulnerability and resilience, and culture will influence the grief experience (Machin, 2009).

The age of the bereaved person can influence the nature of their grief experience. Throughout childhood, grief experiences change considerably as a child moves through phases of cognitive, physical and emotional development (Dyregrov and Dyregrov, 2008). In addition, mental capacity and learning disability will affect the grief experience, or how grief is expressed. This is due to different cognitive processing, emotional capacity and emotional intelligence. Adults with a learning disability, for example, will have a similar type of grief experience in nature to the general population, however it is likely to be expressed differently with anxiety being more prominent (Bonell-Pascual, Huline-Dickens, Hollins, Esterhuyzen, Sedgwick, Abdelnoor and Hubert (2009). Grief is influenced by societal norms, and the way grief is expressed varies across cultures. A broad approach to attitudes and customs in relation to grief is not appropriate because the process of grief is culturally patterned and thus inherent in the experience (Kastenbaum 2012). The co-existence of diverse cultures in the UK requires the professional working with bereaved families to understand the diversity in cultural approaches to the grieving process if support is to be meaningful to the family or bereaved individual.

Freud (1954) was one of the first psychoanalysts to explore the phenomena of grieving and mourning. He compared mourning to melancholia (a mental condition of the era of Freud's studies, described as significant depression of spirits and gloomy forebodings). Mourning was portrayed as a natural process, having an end point. He suggested that interventions were not necessary, were futile, and potentially harmful, when for most individuals the process can be self-regulated over time. Freud's work was pioneering at a time when grieving was not discussed openly. He had a compassionate approach to his studies where the grieving person was placed central to his theorising and the individual's propensity to experience a mental illness was of concern. In addition, the terms of reference that Freud used such as 'lost loved object' and 'object loss' suggested that Freud considered mourning to be a

representative response to the loss of a love severed by death (Fiorini, Bokanowski and Lewkowicz, 2009).

Mourning moving to melancholia was considered extreme by the general populous before, during and after the era of Freud's studies. Interpretations of Freud's work have suggested that he was able to establish that the loss of the love object did not just mean the loss of the connection to the deceased person, but there was a danger to that mourner's sense of self by experiences of intense feelings and emotions (Fiorini et al, 2009). Freud was the first to identify that maintenance of psychological and physical wellbeing through the mourning process linked with ongoing internal attachment to the lost love object (Fiorini et al, 2009). Freud's early concepts on mourning and grief provided a foundation for future research into the grief experience of individuals. However, this foundation has been challenged, in particular, the concept that the bereaved individual 'works' through the grieving process and intervention was not always helpful, which depending on individual need and circumstance, may not be appropriate (Klass et al, 1969; Worden, 2009). Freud acknowledged the shortcomings in the validity of his research such as small numbers of participants (Freud, 1954).

The first modern theorist to share the personal stories and experiences of the dying and their families was Kubler-Ross (1969). Her seminal work culminated in the development of a model of dying and it has subsequently been used to understand grief patterns. Kubler-Ross's research found that many people were reluctant to engage in discussions regarding death and share their grief experiences. She highlighted that death was a taboo or unmentionable subject in the 1960's in Western societies. This reluctance to discuss death remains prevalent today (Kastenbaum, 2012), which is likely to impact on the willingness of friends and family to engage in discussion with those who are dying or are affected by death and bereavement.

Death has been identified as a challenging and distasteful subject for some health professionals, including those working in palliative and end of life care settings across the lifespan, according to a national review of end of life care (Leadership Alliance for the Care of Dying People, 2014). Kubler-Ross in the 1960s onwards was proposing that health professionals needed to be more comfortable and conversant

with the needs of the dying patient (Kubler-Ross, 1969). Her initial research was an ethnographical study, where she undertook observations and interviews with the dying person and some relatives of the dying person. Her theory was developed from these stories of grief, and she conceptualised grief for the dying person as a five-stage sequential process. The stages of dying are denial and isolation, anger, bargaining, depression and acceptance. This model is more commonly referred to as the 'stages of grief', which has caused, and continues to cause, some confusion, with novice practitioners who perceive this theory to relate to grief only and not the experiences of the dying person. While this model was designed to conceptualise the grief experience of the dying person, it also has relevance to bereaved family and friends.

The Kubler-Ross theory of death or grief has been criticised because it is implied that individuals experiencing grief follow similar processes and that these processes are linear and experienced in a sequential order (Bannano, 2009). The theory of grief suggests that individuals would be expected to experience depression and in contemporary society, this is often perceived as a clinically diagnosed depression. The final stage of the model is acceptance and has been criticised by some authors as being unrealistic or unachievable for some bereaved individuals (Klass et al, 1996). Moreover, if this model is applied to the dying, it can be argued that not all patients facing death will feel depressed or will accept their impending death (Worden, 2009). Grief, whether anticipated or after the bereavement event, is a fluid process, with later theorists espousing the individualised grief experience and expanding the five stages of grief to include a range of behaviours and emotions that occur with different individuals at different times (Klass et al, 1996; Parkes & Prigerson, 2010; Stroebe and Schut, 1999; Worden, 2009). In addition, not all people will encounter the full range of proposed experiences.

Along with a colleague, Kubler-Ross developed her original model by exploring the inner and outer worlds of grief and its effect on the bereaved (Kubler-Ross and Kessler, 2005). Similar to Freud's (1954) association of grief with melancholia, depression associated with grief was also considered to be a 'normal process', and more akin to sadness, rather than a clinical depression requiring treatment (Kubler-Ross & Kessler, 2005). This clarification of stage four 'depression' within the theory is more comparable to other theoretical perspectives (Parkes, 1972; Stroebe and Schut, 1999). However, the term 'depression' within the theory remains

misunderstood by most professionals and individuals (Corr, 2015). Stage five of the theory (acceptance) was discussed in later research by Kubler-Ross from a perspective of things never being right again with the world (Kubler-Ross, 2014). She suggested that acceptance of the new reality where the deceased is no longer present was essential to future function and this resonates with other theoretical viewpoints and study findings (Klass et al, 1996; Parkes and Prigerson, 2010; Woodgate, 2006). However, this elaboration from Kubler-Ross on the acceptance stage is not explicit in the commonly interpreted understanding and application of the theory.

Kubler-Ross' theory has been criticised for its wide application without critical appraisal, for example the theory reflects Christian ideologies often referring to seeking meaning through reaching out to God (Corr, 1993). The United Kingdom (UK) is a contemporary, more secular society than it was in the 1960s, and therefore, it may not accurately reflect the diversity of individuals, their spirituality, religious beliefs and cultures. In contrast, the other contemporary theories and models used in clinical practice do not emphasise any specific religious foundation to their concept. In contrast to the Kubler-Ross perspective, grief has been described as an emotional response to the bereavement (Stroebe et al, 1993). However, could be viewed as an oversimplification because reactions to a bereavement experience are much wider than purely emotional experiences. Further exploration of bereavement has resulted in a broader conceptualisation of the impact of grief, which has been described in relation to four categories: feelings, physical sensations, cognitions and behaviours (Figure 1.1) (Worden, 2009).

Feelings	Physical sensations	Cognitions	Behaviours
Sadness	Hollowness in the stomach	Disbelief	Sleep disturbances
Anger		Confusion	Appetite disturbances
Guilt and self-reproach	Tightness in the chest	Preoccupation	Absentminded behaviour
Anxiety	Tightness in the throat	Sense of presence	Social withdrawal
Loneliness	Oversensitivity to noise	Hallucinations	Dreams of the deceased
Fatigue	Sense of depersonalization		Avoiding reminders of the deceased
Helplessness	Breathlessness		Searching and calling out
Shock	Weakness of the muscles		Sighing
Yearning	Lack of energy		Restless hyperactivity
Emancipation	Dry mouth		Crying
Relief			Visiting places or carrying objects as a reminder
Numbness			Treasuring objects that remind of the deceased

Figure 1.1 Categories of grief behaviours (adapted from Worden, 2009)

Grief impacts on every aspect of life and contemporary researchers in the field of grief consider it a physical condition as well as a personal crisis (Kastenbaum, 2012). Somatic complaints such as tightness in the chest and stomach, difficulty swallowing and eating, lack of muscular power and extreme tiredness and lethargy are common (Kowalski and Bondmass, 2007). Initial research explored specific neuroendocrine changes finding that adrenocortical excretion was raised in those individuals actively mourning suggesting a chemical stress response (Hofer, Wolff, Friedman, Mason, 1972). There is the potential that this stress response may exacerbate existing health conditions. Stress-related hormones (cortisol, epinephrine and norephrine) have been found to be raised in individuals who are bereaved leading to increased risk of infectious, cardiovascular and inflammatory illnesses (Hall and Irwin, 2001). A recent integrative review of the literature supports these earlier findings, concluding that physical and mental health outcomes should be anticipated in individuals with complicated grief (Mason and Duffy, 2018).

Although grief is an individual experience, there are commonalities in some experiences that are useful for professionals, friends, family and the bereaved to make sense of their own or an individual's reaction to a bereavement. Worden's (2009) categories of grief behaviour describe a range of 'normal' reactions relating to how an individual might respond to grief. However, if these grief behaviours persist

over a length of time, a complicated grief pattern might be emerging. 'The Tasks of Mourning' model was developed as a result of an alternate approach to the work of Parkes, Kubler-Ross, Bowlby and others, to understand the mourning journey that individuals navigate. The phrase 'task' refers to grief work, meaning that the mourner has work to do and action to undertake; grief in this sense, unlike the linear model offered by Kubler-Ross (1969), is an active, rather than passive process.

The four tasks associated with the grieving process are to:

1. Accept the reality of the loss;
2. Process the pain of grief;
3. Adjust to a world without the deceased;
4. To find an enduring connection with the deceased in the midst of embarking on a new life (Worden, 2009).

There are differing opinions of grief and mourning processes. Parkes (1972) described grief as a fluid process through which bereaved people experience four phases: shock or numbness, yearning and pining, disorganization and despair, and pulling life back together, however, the term 'phase' suggests a more passive process than 'task'. Parkes and Prigerson (2010) suggested one of the most significant characteristics of grief as being 'grief pangs' which are severe but episodic in nature, as opposed to a prolonged depressive experience. This is mirrored in Parkes' the phases of yearning and pining when there is a persistent desire for the person who is deceased (Parkes, 1972). The process of yearning is the act of searching for the one who is lost, as any social mammal might, and it can be prominent throughout a two-year period following bereavement (Parkes and Prigerson, 2010). In the case of the death of a child, this phase of yearning can be much longer than the two years suggested by Parkes (Harper, O'Connor, O'Carroll, 2014; Parkes, 1972; Parkes and Prigerson, 2010).

Grief has been further conceptualised in relation to the idea of 'continuing bonds' initially by Parkes (1972), refined, and developed by Klass et al (1996). Different experiences of continuing bonds include as a sense of presence of the deceased, where they are believed to be spiritually nearby; the place of bereavement dreams in the process; depersonalization where the bereaved feel that they themselves are unreal. Other conceptualisations include derealisation where the world seems unreal;

selective forgetting; and building a new image of the deceased. Continuing bonds have been identified as either facilitative or inhibiting. For some people, continuing bonds will facilitate a healthy grief experience, and for others continuing bonds will hinder or even delay the grieving process (Parkes and Prigerson, 2010). In the context of this thesis, parents who experienced the death of their baby, their loss is not just the death of the baby, but the loss of all the future experiences and 'firsts' that had been anticipated, such as bringing their baby home, first Christmas, starting school and family holidays. The continuing bonds approach to grief is instinctual and facilitative for many grieving parents as they are not ready or willing to 'let go' of their child (Harper, O'Connor, Dickson and O'Carroll, 2011).

1.5.3 Complicated, anticipatory and disenfranchised grief theory

Complicated, anticipatory and disenfranchised grief are less widely considered concepts within the literature in comparison to normal grief patterns and mourning. These less common but complex patterns of grief such as disenfranchised grief and anticipatory grief do not reflect 'normal' grief experiences and are not as widely understood (Gold, 2007). It is likely that many health professionals will not have experience of supporting individuals with more extreme and complex grieving processes.

Anticipatory grief is a reaction that neonatal nurses are familiar with, as most parents of babies on a NICU will experience anticipatory grief to some degree during their baby's stay on the unit. Anticipatory grief is defined as the reaction felt before the actual loss of a loved one (Benfield, Lieb and Reuter, 1976). Most parents whose baby is on NICU are already on a journey of grief as their baby may have had an antenatal diagnosis indicating concern about their baby's health, and they are already likely to be grieving the loss of a normal baby. When mothers go into premature labour, they often begin anticipating the loss of their expected normal birth at term gestation but additionally, some parents will also begin to fear the death of their baby due to prematurity. Not all babies in these scenarios die; however, many parents fear this, which may dominate their thoughts and then they begin to experience anticipatory grief. It has been suggested that anticipatory grief could be viewed as 'positive emotion' as it allows for preparation of impending events and aids coping with an expected loss (Kastenbaum, 2012). It has also been theorised that

this preparatory time of grief may moderate the impact of the loss when it comes, even though pain is still obviously evident (Kastenbaum, 2012).

Lindemann (1944) was the first researcher to recognise and describe anticipatory grief but it is not clear how he developed his theories, as his research methods and participants are not well described. The findings were presented as case study vignettes and they could be considered innovative at the time. While theorists accept anticipatory grief, there is a marked absence of critical debate about its occurrence (Klass et al, 1996; Parkes and Prigerson, 2010). Studies have focused on exploring the extent to which anticipatory grief impacts on parents and whether mothers and fathers are different in their experiences. Two studies relevant to the context of this thesis are Benfield et al's (1976) study and Valizadeh, Zamanzadeh and Rahiminia's (2013) study. The first study involved 101 mother-father pairs who completed a questionnaire about their emotions and feelings in relation to anticipatory grief (Benfield et al, 1976). At the time of the study there was no validated tool for measuring anticipatory grief so it is unclear how the questionnaire was developed and whether it was validated, therefore the findings may not be robust. Further, the study sample was homogenous. The key findings were that there was a difference in anticipatory grief between mothers and fathers, with mothers experiencing significantly greater anticipatory grief than fathers do.

The second study explored 40 mother-father pairs who completed the validated Anticipatory Grief Scale (Valizadeh et al, 2013). The study found no statistically significant difference between mothers and fathers' experiences of anticipatory grief in the NICU. The difference in findings between Valizadeh et al's (2013) and Benfield et al's (1976) studies could be explained by changes in parenting roles for fathers and how fathers have increased involvement during pregnancy and during their baby's care in NICU. In addition, different data collection methods, particularly the use of a tested and validated tool to measure the parent experiences make it difficult to compare the findings of these studies.

Disenfranchised grief can be defined as grief that is not recognised, meaning that the bereaved persons may hide the grief and keep it to themselves (Kastenbaum, 2012). A broader conceptualisation of disenfranchised grief is grief that is not recognised by society (Attig, 2004). It is suggested that all grief becomes disenfranchised over time

(Doka, 2002). This broader view is reflected in parents' accounts of grief in the literature when parents do not perceive that they are hiding their grief, but that society does not see their loss or grief as being comparable to other losses. Exploration of the concept of disenfranchised grief suggested that a range of elements relating to bereavement could be disenfranchised such as relationships, losses, griever, circumstances of the death and the way that individuals grieve (Doka, 1999; 2002). All these elements can have unrecognised consequences such as over-intensified reactions, the inability to participate in the dying process and concurrent crises (Doka, 2002).

The 'social norms' of grief exist and there is a sense of a lack of legitimacy regarding parental grieving over the death of a new-born baby. It is questionable whether grief should be regulated by society in this way or if grief should be subject to a hierarchical agenda (Robson and Walter, 2012). This lack of legitimacy to be able to grieve in a personally appropriate way is an unexpected and unwelcome challenge faced by parents and family grieving over their most precious lost 'love object' (Lang et al, 2011). Disenfranchised grief has been described as a social, empathic, political and ethical failure (Attig, 2004). However, this hierarchy of grief is a cultural phenomenon in which differing cultures develop their own map of grief, leading to clear expectations regarding how an individual should grieve (Doka and Martin, 2002). Most of the literature on disenfranchised grief is drawn from the United States (US) and the UK. However, research on disenfranchised grief in the US resonates with parental experiences in the UK and across Europe (Lang et al, 2011). Furthermore, it has been suggested that work is needed to empower disenfranchised grievers to be enfranchised in their emotions and feelings by supporting them towards hope and resilience through 'soul work' and 'spirit work' (Attig 2004). These terms may disengage some secular populations because the terms soul and spirit are often assumed to have religious affiliations.

Reflection Point 1.1: experiences of disenfranchised grief

My encounters of caring for parents who appeared to be exhibiting disenfranchised grief suggest that it is encountered in diverse cultures but in a different way. I have cared for mothers in the Bangladeshi community who are conditioned to 'hold down' their emotions soon after the burial of their baby. In these cases, accepting a visit from a bereavement nurse was a secret matter but once an opening was given for conversation about their baby, a rush of dialogue and emotion was released. These mothers were told that they had to leave their sadness behind quickly, but it was there, held inside. Equally, I have cared for White British mothers and fathers who felt that family and friends did not think that the depth of their grief was an appropriate reaction to the loss of the brief life of their baby. These parents felt that their grief was silenced, ignored and not accepted.

It can be postulated that parents in the study undertaken as part of this thesis may be experiencing grief outside of the 'normal' perceived range, therefore a consideration of other intensities of grief is required. The concept of a grieving style that moves out of perceived normality has generated debate and discussion in the literature (Bowlby, 1998; Machin, 2009; Worden, 2009). This mode of grieving outside expected normal patterns is referred to by several descriptors such as disordered mourning, melancholia (Freud, 1954), complicated grief (Parkes and Prigerson, 2010), chronic grief, pathological grief (Bowlby, 1998) and prolonged grief disorder (Machin, 2009). For the purpose of this thesis, the term 'complicated grief' will be used. The experience of complicated grief is difficult to measure due to the individual nature of a grief journey. It cannot be defined by the passage of a specific time period or by one particular behaviour, nor can assumptions be made that a specific situation will result in the individual experiencing a complicated grief pattern.

Complicated grief has been defined as "prolonged distress and disability in connection with bereavement" (Guildin, O'Connor, Sokolowski, Jenson, Vedsted (2011, p.1). In its severest form, complications of grief become a disorder that requires significant psychological intervention and possibly pharmacological treatment. Symptoms of this mode of grief may include ongoing preoccupation with memories of the deceased, severe distress arising from reminders of the deceased, intense pining, lack of self-care, aggressive outbursts and ongoing withdrawal from social circles and society (Parkes and Prigerson, 2010). What is significant about these symptoms is the impact of symptoms on social, occupational and other areas of essential every day functioning. Some individuals may progress to experience

depressive disorder and post-traumatic stress disorder (PTSD). Therapists providing interventions for individuals with grief disorders can draw on a range of tools to assess the intensity of grief, including the Index of Complicated Grief (Parkes and Prigerson, 2010), the Prolonged Grief Index, and the Adult Attitude to Grief scale (Machin 2009).

Different bereavement situations predispose individuals to increased risk of a complicated grief experience; for example, child bereavement, sudden death, concurrent crises, issues of age and gender, ambivalence and reduced material resources (Machin, 2009; Sanders, 1993). The participants in this doctoral study were at increased risk of a complex grief pattern because their child had died. In addition, some participants may have experienced a sudden or unexpected death, and some participants may have had additional risk factors. It was likely that some participants would experience a complicated grief pattern, however these participants' experiences were important and, if possible, they had to be represented within the study sample so that variations in parental grief journeys would be characterised in the findings.

1.5.4 Application of grief theories to this study

There are several conceptualisations of how grief and mourning can be explained and understood. The theoretical perspectives that were drawn on to guide this study and which were considered initially to be best suited to explain the study findings are the continuing bonds theory (Klass et al, 1996) and the dual process model of coping with bereavement (DPM) (Strobe and Schut, 1999).

Research about childhood patterns of grief, where children have lost a parent during childhood, has found that both younger children and adolescents try to make sense of the bereavement experience in their own way for example metaphorically holding the deceased parent with them (Klass et al 1996). Similarly, in research with adults, it was identified that this process of 'holding the deceased close' was not unique to children (Klass et al 1996). A model of continuing connections with the deceased was thought to be useful in order to understand adult patterns of grief and mourning. This model of grief does not judge dependence as unfavourable, rather interdependence is noted to be sustained after the death of a loved one and is respected.

Bereaved parents often continue to include their dead child in their descriptions of their family to others and in their own and their children's daily lives (Klass et al, 1996). This approach of describing 'we have three children, but one is no longer with us' is a situation with which grieving families appear to be entirely comfortable. However, there is the potential for parents in this situation to experience social isolation or criticism for continuing to keep a place for their deceased child in their lives as this can be deemed unusual and unsavoury to society in general. Some parents may have different portrayals of the place of their deceased child in their inner (psychic) and social worlds. Klass et al (1996) narrates and interprets bereaved parents' experiences in four areas: newly bereaved, into their grief, well along in their grief and resolved as much as it will be. These four areas are explored from both inner and social world perspectives. Like many other theories and models of grief, continuing bonds sketches a linear journey along the experience but Klass et al assert that flexible movement back and forth between the four areas is necessary and expected (Klass et al, 1996).

Where some grief theories have suggested an end to grief with acceptance, the continuing bonds theory is more fluid in terms of the final outcome for the individual (Kubler-Ross, 1969; Freud, 1954, Klass et al, 1996). Continuing bonds recognises that for some individuals the grief experience does not end and does not necessarily indicate a pathological grief experience. Whilst grief might not end, this does not mean that grief is continuous and at the same intensity throughout the individual's lifetime (Rosenblatt, 1996). The continuing bonds theory confirms Parkes idea of grief pangs, with strong, recurrent surges of grief in different periods of life (Parkes and Prigerson, 2010; Rosenblatt, 1996).

The continuing bonds theory was adopted to support this study because it is a fresh perspective on grief experiences and different to previous theoretical understanding. Continuing bonds rejects the idea that a severing of bonds with the deceased is necessary for future function and attachments. This approach is reflected in bereaved parents' narratives (Woodgate, 2006). The traditional concept in modern Western societies that grief is work that needs to be completed and finished and that the feelings of grief should disappear permanently at some point, is rejected. However, grief is not generally continuous in its intensity beyond the first few weeks, even after a traumatic or significant death. Rather, it is acknowledged that these

strong feelings from the early weeks of grief can reoccur at any time afterwards (Klass et al, 1996). It is acknowledged that certain triggers may move an individual back into the early intensity of grief after some time. These triggers are individual to the person but there are some commonalities of experiences such as birthday of the deceased, anniversary of the date of death, Christmas, Eid or other religious festivals. When considered in the context of a bereaved parent whose child has died, there are other additional triggers. These often take the form of missed experiences such as holidays, the start of the school year or when the child would have started school and seeing pregnant friends and relatives (Kohner and Henley, 2001). The continuing bonds theory of grief offers a unique perspective on health professionals' understanding bereaved parents' experiences.

The second theoretical perspective adopted to support this thesis was the DPM, which presents a range of behaviours and emotions experienced during the grief journey. Perceptions within many cultures assume a finite duration should be attached to the grieving process, however, Stroebe et al (1993) propose that a grief timeline (in months and years) does not represent individual experiences. Their studies found that the bereaved continued to experience grief work for several years, and their attachment with the deceased remained. There are similarities between the continuing bonds theory and DPM, however DPM offers some alternative foci concerning the two main behaviours that the researchers determined grieving individuals to experience (Stroebe and Schut, 1999).

The DPM describes coping behaviours in grieving individuals and good, versus poor adaptations to the bereavement experience. The DPM maps the experience of coping with everyday life and how grieving people will lean towards being either loss-orientated or restoration-orientated. This tendency might differ from day to day, and Strobe and Schut (1999) hypothesised that the healthiest way to grieve is to oscillate between the two directions (Figure 1.2). The DPM has been studied in several different contexts and populations and has been used to explore bereavement across genders. Evidence suggests that women tend to be loss-orientated and that men tend to be restoration-orientated, however this will not always be the case (Strobe, et al, 2001). This model does not subscribe to a staged or phased process and movement between emotions and behaviours is to be expected, without placing an expectation on the grieving person to move onto another stage. This expectation of

fluidity in the process fits better with an individualised approach to understanding experiences and planning care delivery, support and therapy.

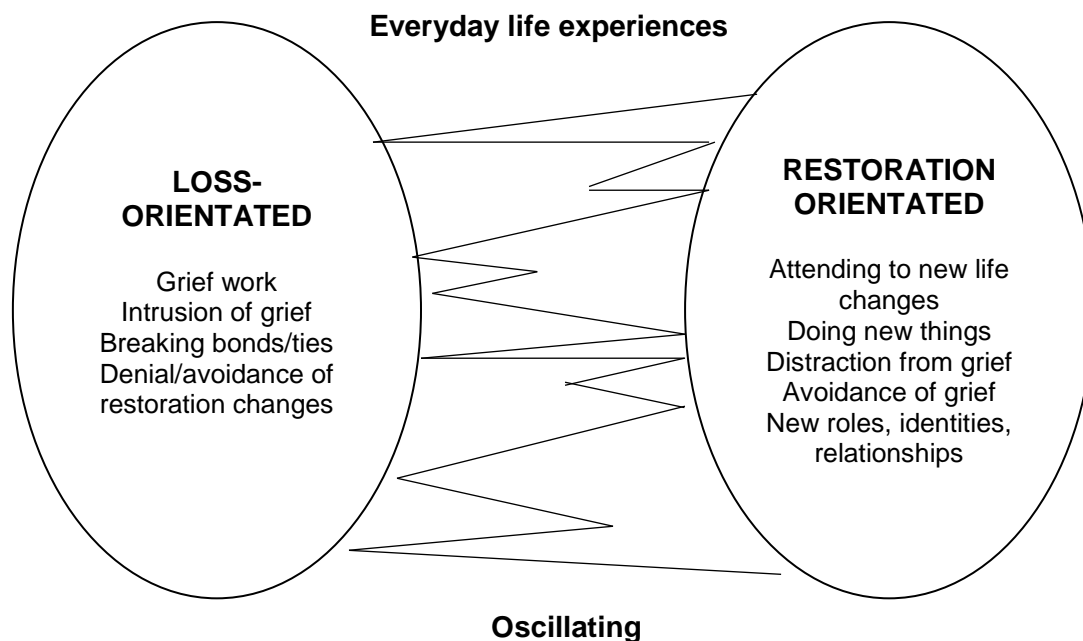


Figure 1.2 The Dual Process Model of Grief (Strobe and Schut, 1999)

The continuing bond theory and DPM are used in later chapters and applied to the study findings.

1.6 Thesis overview

This thesis is about parents' experiences and perceptions of support during and after the death of their baby. To date, the focus of research in the neonatal end of life care setting has been on ethical decision-making and end of life care for the baby and their family. Ensuring both the psychological and physical health and wellbeing of parents who have experienced this life-changing experience requires detailed understanding of their experiences in order to ensure the support offered is not only delivered sensitively but is informed by research.

A scoping review of studies exploring parents' experiences during/after the death of a child is presented in Chapter 2, with 19 studies reviewed. The findings of the studies reviewed were charted, summarised and reported on in order to identify gaps in the evidence base and examine the extent, range and nature of contemporary research activity (Arksey and O'Malley, 2005). The findings of the review have been drawn on

to contextualise the findings from the study undertaken as part of this thesis, presented in Chapter 7.

Chapter 3 addresses the ethical considerations for the study; a designated chapter was appropriate to discuss in-depth challenges of undertaking a study with vulnerable participants at risk of psychological harm from participating in research. In addition, strategies used to ensure my well-being when exploring an emotional subject are discussed.

The empirical study designed to explore parental experiences and support needs when their baby has died is reported in Chapter 4. This chapter included the study design and methodological considerations, with the application of the methods reporting on how the study was undertaken presented in Chapter 5.

Findings from the analysis of seven participants' narratives are presented in Chapter 6. The four superordinate themes, 'the enormity of grief', 'being isolated', 'trying to survive' and 'routes to an improved future', are presented. The Neonatal Grief Sandstorm is offered as a visual tool to represent how parents survive the death of their baby and navigate life afterwards. Chapter 7 offers a discussion of the findings and finally, Chapter 8 concludes with the key messages that arise from this doctoral thesis.

1.7 Summary

This chapter has presented the theories that were considered relevant to exploring the research aims and objective of the study in this thesis. Two theoretical perspectives, the continuing bonds theory and the DPM theory have been discussed and analysed in relation to grief, and human attachment has been examined in the context of immediate parent -baby attachment at birth. A range of interpretations of theoretical concepts has been offered, particularly in the context of individuals where their responses are outside the 'usual' pattern of attachment, loss and grief. The unique significance of the parent-child relationship and attachment makes comparing parents who experience neonatal bereavement and assuming they will progress through a mourning process and emerge able to continue functioning is misplaced. The theories presented and how they have shaped this thesis will be revisited throughout.

Chapter 2 - A scoping review of the literature

2.1 Introduction

As identified in Chapter 1 the support available for bereaved parents in the UK is variable. Identifying and summarising the current evidence-base relating to parents experience of the support available has the potential to inform local and national practice development in relation to bereavement support services in a neonatal care context, and influence future research directions. The scoping review was undertaken to map the current evidence in relation to the experiences of parents during and following the death of their baby, and identify gaps in the literature. More importantly, the scoping review informed the direction of the research undertaken as part of this thesis. This chapter presents the aim of the scoping review, methods, procedures, findings and discussion of the scoping review. Limitations of the scoping review will be considered.

2.2 Aim and objectives

The broad aim of the scoping review was to identify empirical studies that have explored parents' perspectives and experiences of support both in the neonatal unit at the end of life and once parents are at home, after the death of their baby. The following questions guided the review:

- What is the impact on parents' lives following the death of a baby?
- What support strategies have been implemented and evaluated in neonatal end of life and in the bereavement period?

2.3 Review context

Choosing the most appropriate strategy to review the literature should be guided by the purpose of the review and over 14 types of reviews have been identified including, narrative, systematic, rapid structured and scoping reviews (Grant and Booth, 2009). A systematic review is the most robust method to undertaking a literature review when answering clinical questions (Centre for Reviews and Dissemination [CRD], 2009). Systematic reviews summarise and synthesise

research findings in order to inform policy makers, professionals and patients of the best available evidence upon which healthcare decisions can be based (Centre for Reviews and Dissemination (CRD) 2009). Whilst systematic reviews are the gold standard optimum strategy for robust literature reviewing, they are not always the most appropriate review approach. Narrative and rapid structured reviews tend to report on a small selection of studies due to time and resources constraints. Scoping reviews include a comprehensive and robust search strategy but unlike systematic reviews do not undertake a synthesis of the evidence (CRD 2009). When the purpose of the literature review is to inform and guide a prospective empirical study, the method of review should be an approach that blends with the planned research methodology. In the case of this thesis, the empirical study has adopted an interpretative phenomenology analysis (IPA) research methodology. Therefore, a scoping review was the most appropriate strategy; the rationale is presented below.

A scoping review has been defined as “preliminary investigative processes that identify the range and nature of existing evidence and help in the formulation of a research question(s)” (Davis et al, 2009, p1387). A contemporary theorist in the field of IPA suggests that the precursor literature review prior to undertaking an IPA study is normally brief and often evaluative (Smith, Flowers, Larkin, 2009). The aim of the literature review in IPA is to identify gaps in the knowledge and identify the strengths and weaknesses of the evidence of the topic of interest rather than an in-depth analysis, which has the potential to influence future IPA research (Smith et al, 2009). The volume and characteristics of the evidence base can be established by undertaking a scoping review and summary of the included papers can be offered. Scoping reviews can help proposed studies to build on existing evidence and add a unique contribution to the existing body of knowledge. They can be used to map key concepts underpinning prospective research plans and questions, and to clarify definitions and concepts about a topic. Scoping reviews have been referred to as evidential reconnaissance, where a scouting exercise with clear structures is undertaken (JBI, 2015). Scoping reviews are relevant to both emerging and established fields of health care (Colquhoun, Levac, O’Brien, Strauss, Tricco, Perrier, Kastner and Moher, 2014).

Scoping reviews are particularly useful when there is a paucity of the highest quality evidence, for example, randomised control trial (RCT), meaning that a systematic

review of effectiveness would be difficult to undertake (Levac, 2010). The focus of this thesis and therefore the anticipated literature is an area of healthcare where RCTs are an unlikely research methodology choice. Scoping reviews commonly include a range of research methodologies and study designs (Pham, Rajic, Greig, Sargeant, Papadopoulos, McEwen, 2014). Scoping reviews are a relevant approach to reviewing the evidence as a precursor to consultation on policy and practice and when there is a limited timeframe and resource (Armstrong, Hall, Doyle, Waters, 2011; Levac et al, 2010). Therefore, a scoping review was a suitable strategy for this thesis, where it was anticipated that multiple study designs would be included. Four common reasons for choosing a scoping study include to:

1. Examine the extent, type and range of the evidence;
2. Determine whether a systematic review would be valuable;
3. Summarise and disseminate the evidence base;
4. Identify research gaps in the current evidence base.

(Arksey and O'Malley, 2005)

2.4 Methods

This section will describe the methods used to undertake the literature review using the Arksey and O'Malley (2005) original framework for undertaking scoping reviews later expanded by Levac et al (2010).

2.4.1 Design

The five stages of the framework developed by Arksey and O'Malley (2005) were used to direct the scoping review to ensure the process was undertaken rigorously. Consideration was also given to subsequent enhancements to the framework, which offered greater clarity relating to the practicalities associated with each stage (Levac et al, 2010), presented in Figure 2.1. Stage three of the framework was completely utilised because a team approach to study selection was not possible in this PhD study, although any uncertainties relating to whether to include or exclude articles were discussed in supervision meetings. Stage six was not used in this scoping review, as consultation following the review was not appropriate to this study.

Stage	Arksey and O'Malley Framework	Levac et al's enhancements
1	Identifying the research question	Clarifying and linking the purpose and research question
2	Identifying relevant studies	Balancing feasibility with breadth of comprehensiveness of the scoping review
3	Study selection	Using an iterative team approach to selecting the studies and extracting the data
4	Charting the data	Incorporating a numerical summary and qualitative thematic analysis
5	Collating, summarising and reporting the results	Identifying the implications of the study findings for policy, practice or research
6	Consultation (optional)	Adopting consultation as a required component of scoping study methodology

Figure 2.1 Assimilation of scoping review frameworks

The first stage of a literature review is to develop a clear focus, which includes developing a review question or clear aims and objectives. The background to this review has been presented in Chapter 1, which highlighted the significance of attachment between parent and infant and the impact of losing this attachment when the death of their baby occurs. In addition, a range of theories of grief and mourning were critically evaluated, and were considered when developing the review aims and guiding questions, presented in Section 2.1.

2.4.2 Sampling methods

The sampling methods were guided by stage two of Arksey's framework: identifying relevant studies, with a comprehensive approach to the process (Arksey and O'Malley, 2005). In order to develop a robust search strategy, the PICO and PEO frameworks were used to facilitate the development of clear inclusion and exclusion criteria and search terms. PICO is normally used when the goal is to formulate a quantitative research hypothesis and PEO used when formulating primarily qualitative research questions (Khan, Kunz, Kleijnen and Antes, 2003). It was anticipated that the evidence base would be mostly qualitative; however, all types of study designs were included. PEO was chosen as the most appropriate framework for this scoping review and to assist development of the search strategy presented in Figure 2.2.

		Suggested use	This thesis
P	Populations/Problems	Who are the users, community, patients, symptoms, gender	Parents, carers, family, health professionals
E	Exposure	Type of exposure e.g. emotional abuse	End of life care, bereavement, grief,
O	Outcomes	What are you looking to measure? e.g. response to treatment, quality of life	Experiences, support systems, interventions, therapy

Figure 2.2 The PEO Acronym (Bettany-Saltikov, 2012)

2.4.2.1 Selection criteria

The initial search was conducted in 2012, but the search and results were updated in 2018. Selection criteria were broad to reflect different study designs in relation to explore the experiences of neonatal end of life care, bereavement or support strategies after the death. Parental experiences of early pregnancy loss and the reasons for losing the baby are diverse; in addition, the care given and care environment are very different to neonatal deaths therefore, studies of loss during pregnancy were not included. The inclusion and exclusion criteria are listed below.

Inclusion criteria:

1. Studies of parents', carers', guardians' or foster parents' experiences of neonatal death, bereavement and grief;
2. Studies that have evaluated parents' experiences of the support or support services available during neonatal end of life care and after the death of their baby;
3. Studies that categorise support offered to parents from a professional or lay perspective;
4. Studies published in the English language;
5. Studies published after 2002.

Exclusion criteria:

1. Studies exclusively exploring parents' experiences of death in-utero, still birth and pregnancy loss;

2. Studies measuring decision-making, rather than parent experiences during neonatal end of life care;

2.4.2.2 Sampling strategies

Studies were identified by searching the four key health and social care databases, CINAHL (Cumulative Index of Nursing and Allied Health Literature), MEDLINE (Medical Literature Analysis and Retrieval System Online), PSYCINFO (database of abstracts of literature in the field of psychology); and SCOPUS (database of medicine, social sciences, art and humanities), which index a wide range of health related topics and study designs. The key search terms are presented in Figure 2.3. Truncation, wildcards and MeSH headings (medical subject headings) were used as appropriate to facilitate a robust search strategy. A 10-year period, January 2002 to December 2012, was initially searched because studies within this time period are more likely to reflect contemporary health policy. This was extended to December 2018 when the searches were updated. Search terms were developed from initial conception by using the PEO acronym (Khan et al, 2003). Each search was saved, to enable the searches to be updated by rerunning the search with identical methods.

Population 1	Population 2	Theoretical perspectives	Experiences	Interventions
Parent Mother Father	Bab* Infant Neonat* Newborn Perinatal Profession*	Grief Loss Bereave* Death Dying Palliative End of life	Perception Experience View Thought Perspective	Support Counsel* Help Therap* Contact Guidance Advice

Figure 2.3 Search Terms

Although database search engines are well developed, some relevant papers may not be identified from the data base searches due to the way key words are indexed. For example, if the title of the paper is ambiguous or does not describe the study adequately, those papers may not be indexed appropriately (Aveyard, 2007). In addition, it is usual to find a relevant study by chance even with robust searching

strategies (Montori, Wilczynski, Morgan and Haynes, 2004). To ensure a comprehensive search was undertaken additional approaches are recommended including reference lists, hand searching of key journals and utilisation of existing networks, organisations and conferences (Arksey and O'Malley, 2005). Multiple search strategies were undertaken to increase the likelihood of finding all the relevant studies.

Further studies were identified by searching authors with an interest in the topic, for example, where multiple studies had been found in the data base search by the same researcher(s) (Aveyard, 2007). Hand searching of Journal of Perinatology (from 2002-2018) and bibliographies of included papers were undertaken. This reduced the risk of sampling bias in relying solely on database searching. Journal of Perinatology was chosen because two of the papers identified from the data base search were from this journal. This technique has been referred to a snowball sampling, because the strategy develops as the search progresses (Greenhalgh and Taylor, 2005). In addition, attempts were made to search the grey literature, to locate unpublished material, websites, editorials, reports and additionally social media such as twitter chats, as they can lead to empirical studies (Gray, 2014). National guidance and third sector guidance, rather than empirical evidence, was located and although provided contextual information, included in Chapter 1, was excluded from the review. Other sources of grey literature such as social media information and editorials were not empirical research so also excluded.

2.4.3 Data extraction form

The process of ensuring consistency in extraction of data from each of the included studies can be achieved by developing a data extraction form, with template available from the CRD (2009). The data extraction form template was adjusted to reflect the process of undertaking a scoping review, which excludes synthesis and quality appraisal, and meet the specific needs of this scoping review (Appendix I). Data reference and management software in the form of EndNote Reference Manager was used to collate, categorise and store the search results at various stages in the review. The use of reference management software enabled a robust approach to storage of results and maintenance of a search log (Gray, 2014). When considering the initial number of abstracts yielded in the scoping review, this software aided the tracking and organisation processes in various stages of the review.

2.5 Procedures

This section will discuss the procedures for paper selection and data extraction. Unlike a systematic review, the scoping review process does not assess the included studies in relation to quality appraisal or data synthesis.

2.5.1 Selection of papers

Selection of studies was guided by stage three of the Arksey's framework (Arksey and O'Malley, 2005). The updated electronic searches of the four databases (December 2018) yielded a total of 2151 returns which was significantly more than the 388 in 2012; each title was screened, and studies where the focus was not neonatal bereavement were removed, resulting in 387 titles related to the review focus. The abstracts of these titles were assessed to establish if the study met the inclusion criteria, with 178 full study reports retrieved for detailed assessment. Studies were excluded for the following reasons: duplicates, studies that did not relate to live births of babies (stillbirth, termination, miscarriage), studies not relating to neonates (infants and children) and studies that did not relate to parents' experiences. Any uncertainties regarding inclusion and exclusion criteria were discussed with my supervisors. Following abstract screening and review of the full papers, 16 studies were included. A further three studies were identified from the hand searches and any significant authors and references of included studies. A total of 19 studies were included. The process of study selection is presented in a flow chart in Figure 2.4.

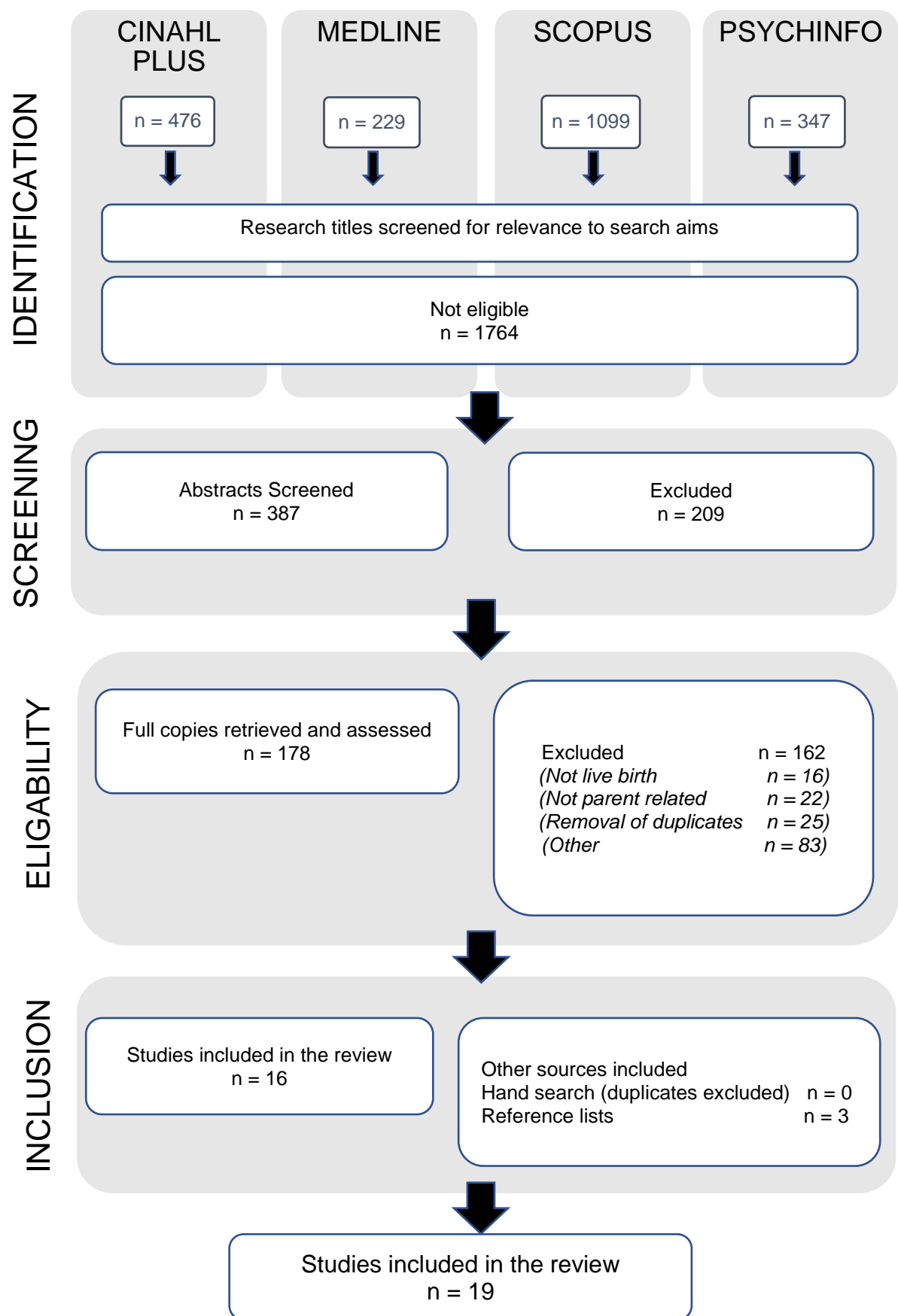


Figure 2.4 Study Selection

2.5.2 Charting the data

Data extraction of the included studies was guided by stage four of Arksey's framework: charting the data (Arksey and O'Malley, 2005). This process involves charting key findings from the studies. An iterative process was used to chart the data; the data extraction form was updated as each study was reviewed and analysed. In addition, data charting should be expanded to include numerical summaries and narrative summary of key findings (Levac et al, 2010). The numerical summaries are presented alongside the findings in section 2.5, in Tables 2.3, 2.4, 2.5, 2.6 and 2.7.

2.6 Findings

This section presents an outline of the review studies. The themes and categories that emerged from data extraction, charting and summarising of the studies will be reported.

2.6.1 Overview of review studies

A total of 19 studies were included in the scoping review. Table 2.1 presents the characteristics of the review studies, including geographical location of the study, participants and study setting. Table 2.2 presents the aims, methods and key findings from the review studies.

Table 2.1 Characteristics of the studies

Author(s)	Title	Country	Participants
Abdel et al (2018)	Mothers' Lived Experience of Losing a Newborn Infant in Jordan	Jordan	12 mothers
Abraham et al (2017)	"You Can Only Give Warmth to Your Baby When It's Too Late": Parents' Bonding With Their Extremely Preterm and Dying Child	Switzerland	20 parents (12 mothers, 8 fathers)
Ano et al (2018)	The effects of peer support on post-traumatic stress reactions in bereaved parents	Finland	110 parents (67 mothers, 43 fathers)
Armentrout (2007)	Holding a Place: Parents' Lives Following Removal of Infant Life Support	USA	15 parents (11 mothers, 4 fathers)
Baughcum et al (2017)	Perspectives From Bereaved Parents on Improving End of Life Care in the NICU	USA	45 parents (29 mothers, 16 fathers)
Branchett et al (2002)	Neonatal palliative and end of life care: What parents want from professionals	UK	57 parents (53 mothers, 4 fathers)
Brosig et al (2007)	Infant end of life: the parents' perspective	USA	30 parents (18 mothers, 11 fathers, 1 aunt)
Currie et al (2016)	Parent Perspectives of Neonatal Intensive Care at the End-of-Life	USA	10 parents (7 mothers, 3 fathers)
Einaudi et al (2010)	Parental experience following perinatal death: exploring the issues to make progress	France	12 parents (10 mothers, 2 fathers)
Glaser et al (2007)	Loss of a preterm infant: psychological aspects in parents	Switzerland	19 parents (10 mothers, 9 fathers)
Gold et al (2016)	Depression and Posttraumatic Stress Symptoms After Perinatal Loss in a Population-Based Sample	USA	609 mothers (377 bereaved, 232 control)
Kavanaugh et al (2005)	Perinatal loss in low-income African-American families	USA	23 parents (17 mothers, 6 partners)
Lang et al (2011)	Perinatal loss and parental grief: the challenge of ambiguity and disenfranchise	Canada	13 couples

Author(s)	Title	Country	Participants
Lundqvist et al (2002)	Both empowered and powerless: mothers' experiences of professional care when their newborn dies	Sweden	16 mothers
Pector (2004)	How bereaved multiple-birth parents cope with hospitalization, homecoming, disposition for deceased and attachment to survivors.	USA	70 parents (66 mothers, 4 fathers)
Richards et al (2015)	Mothers' perspectives on the perinatal loss of a co-twin: a qualitative study	UK	14 mothers
Robertson et al (2011)	Provision of bereavement care in neonatal units in the UK	UK	330 professional responses from neonatal units
Swanson et al (2002)	How mothers cope with the death of a twin or higher multiple	Australia	66 mothers
Swanson et al (2009)	How couples cope with the death of a twin or higher order multiple	Australia	52 couples

Table 2.2 Summary of studies

Author	Aim	Methods	Key findings
Abdel and Al-Gamel (2018)	Description of lived experience of bereaved mothers. Analyse how mothers reconstruct the meaning of their loss.	Descriptive phenomenological approach. Purposive sampling. Interviews. Thematic analysis.	Longing and grieving, the adaptive work of coping and moving forward but with a scar were the three themes arising. Spirituality was a component of sense-making about their experiences. Discussion suggested a need to improve the provision of quality of bereavement care.
Abraham and Hendricks (2017)	How parents experience the dying trajectory, parenthood and how professionals can facilitate bonding at the end of life.	Retrospective qualitative study based on symbolic interactionism. Interviews with ethnographic aspects. Analysed using content analysis.	Importance of parenthood emphasised in two phases of after baby's transfer to NICU and end of life phase. Parents experienced a phase of uncertainty after transfer to the NICU, end of life related to parental needs at this time and professional support relating to end of life and psychological care around death.
Ano, Malmisuo and Kaunonen (2017)	Describe the impact of peer support on post-traumatic stress disorder in parents who have experienced the death of a child.	Quantitative design with survey before and after a family weekend intervention. Purposive sample. Analysis undertaken with SPSS.	No statistically significant association with parents' PTSD symptoms 2 weeks before and after the weekend intervention. 66% of parents estimated they had received 'much' or 'very much' support from the weekend. Group discussions and the memorial service were most useful.
Armentrout (2007)	How do parents describe their experiences of making decisions about life support withdrawal and how does this influence parents' daily lives after the death.	Grounded theory design. Theoretical sample. Interviews either phone or face-to-face. Constant comparison method of analysis.	Making decision to remove life support facilitated parents to decide how the final hours of life were spent. Grief experienced by study participants reduced as time passed. Keeping their baby as part of the family was of key importance to parents.
Baughcum et al (2017)	Parents' perspectives of their infant's end of life experiences in NICU	Mixed method design. Survey and/or interview data. Analysis using <i>t</i> -tests and χ^2 . Content analysis for qualitative data.	Parents wanted to be partners in care and highlighted their experiences where communication was mostly positive. Relationships with staff were central to care. Parental insight into optimal bereavement support in NICU included private room, less interruptions, sibling support and materials about grief.

Author	Aim	Methods	Key findings
Branchett and Stretton (2012)	Determine what parents experienced relating to neonatal palliative and end of life care.	Qualitative study carried out via online community. Two questions only. Thematic analysis of responses.	Empowerment was facilitated through accurate and timely information. Sensitive guidance from staff was appreciated. Parents' perceived their baby's problems were their fault. Creating memories were very important as keepsakes for a lifetime.
Brosig et al (2007)	Identify factors important to parents in end of life care.	Mixed methods design. Parents completed questionnaire and semi-structured interview. Data analysis not described.	Honesty about the reality of baby's condition and being empowered in decision-making affected whether end of life was viewed positively. Faith and trust were key to the parent-professional relationship.
Currie et al (2016)	Explore parents' perceptions of end of life care and pediatric palliative care in the NICU.	Qualitative descriptive design. Purposive sampling. Semi-structured interviews. Content analysis within naturalistic paradigm.	The 'ups and downs' of parented were highlighted including barriers and what being a parent in NICU was like. Decisions in the NICU were difficult and brought criticism from friends and family; some parents were left out of decision-making. Support reported nurses prepared parents for death, friends and family were also a support in the NICU.
Einaudi et al (2010)	Understand parental attitudes, needs and ethical issues at end of life. Assist in development of interventions for bereaved families.	Qualitative descriptive study. Questionnaire based on Delphi method. Ethical analysis of interviews undertaken.	Challenges of accepting the announcement of the seriousness of the diagnosis. Involvement of the family circle needed – grandparents and siblings support important. Importance of time to say goodbye to their baby. Differences in follow-up and support after death.
Glaser et al (2007)	Exploration of parent preoccupation of suffering after the loss of a preterm infant.	Qualitative descriptive design. Purposive sampling. Semi-structured interviews. Context analysis.	Different experiences in emotional, cognitive and social aspects reported in the acute phase. Emotional experience at the time of loss is intense. More positive changes 3.5 – 6.5 years later but sadness remains.

Author	Aim	Methods	Key findings
Gold et al (2016)	Characterization of depression and PTSD in perinatally bereaved mothers.	Large, epidemiological quantitative design with control group. Survey instrument. Analysis using <i>t</i> -tests and χ^2 .	High and persistent levels of distress at nine months post-loss. Bereaved mothers are four times more likely to experience depressive symptoms than non-bereaved mothers. African-American mothers less likely to be receiving treatment for this.
Kavanaugh and Herschberger (2005)	Examine the experience of low-income parent's perinatal loss. Describe how life stressors influence caring needs.	Qualitative phenomenological study. Interviews. Colaizzi's approach to analysis.	Parents described their experiences of intense emotions after the death. Many parents relied on their spirituality to deal with the loss. Health professionals should be aware of additional stressful events and intervene appropriately.
Lang et al (2011)	Explore sources of ambiguity and disenfranchised grief related to perinatal loss.	Qualitative study using unstructured interviews. Interview data analysed using content analysis approach.	Health professionals perceived by parents as minimising the loss by treating it as a medical event. Numerous sources of disenfranchised grief were found: in marriages, with professionals and with family.
Lundqvist et al (2002)	Illuminate mothers' lived experiences of professional care received whilst facing reality of losing their baby	Qualitative study using interviews. Analysis using hermeneutic phenomenological method.	All mothers described both feelings of empowerment and being powerless. Feelings of empowerment emerged from health professional empathy.
Pector (2004)	Elicit bereaved parents' perceptions regarding support, decisions, discharge and later coping	Mixed methods study. Narrative email survey with quantitative and qualitative analysis.	Lack of communication between health professionals and parents about the loss. Hospitals and social workers can provide valuable support. Parents faced major challenges with attachment to living twin.
Richards et al (2015)	Gain in-depth understanding of the experiences of mothers who have had a loss from a twin pregnancy.	Qualitative design based on interpretivist epistemology. Purposive sampling. Semi-structured interviews. Thematic analysis.	Bereaved mothers of twin loss have different needs to those who lost a singleton. Discontinuity of care team was difficult. Traumatized feelings early in the loss leading to feelings of numbness and helplessness.
Robertson et al (2011)	Establish what bereavement care services are available in neonatal units in the UK	Quantitative study. Questionnaire survey data analysed using SPSS.	More respondents felt that the training they received was inadequate rather than excellent. 99% of units provided parents with some memories after death. Formal psychological support offered to 45% of bereaved parents.

Author	Aim	Methods	Key findings
Swanson et al, (2009)	Explore how couples cope with the death of a twin or higher order multiple. Comparison of mothers' and fathers' coping.	Mixed methods study. Questionnaire – depression grief scale. Unstructured interviews. Data analysis not described.	Differences between mothers and fathers in current and retrospective depression and perinatal grief. Fathers' experienced low levels of depression (current/retrospective); mothers reported low levels current depression but high retrospective.
Swanson et al (2002)	Explore nature of bereavement in mother who lost one of multiples, means of coping and how to improve family support.	Mixed methods study. Questionnaire – beck's depression and perinatal grief scale. Interviews and focus groups. Data analysis <i>t</i> test.	Importance of spirituality after their loss. Sense of betrayal by medical establishment and feeling of being unprepared for deaths.

The included studies were all undertaken in developed societies including Europe (and the UK), North America, Australia and the Middle East. Table 2.3 presents the data extracted from the review studies in relation to geographical location.

Table 2.3 Scoping review - geographical location of the studies (n=19)

Location	UK	Other European	North America	Australia	Middle East
Number of studies	3	5	8	2	1

The nature of the relationship of study participants to the deceased baby or child in the included studies are presented in Table 2.4. Study participants were primarily parents, but one study also included health care professionals surveyed on support offered to parents (Robertson et al, 2011). Fathers views were well represented across the studies, with couples participating in 13 of the 19 studies (Abraham and Hendricks, 2017; Aho et al, 2017; Armentrout, 2007; Baughcum et al, 2017; Branchett and Stretton, 2012; Brosig, Pierucci, Kupst, Leuthner, 2007; Currie et al, 2016; Einaudi et al, 2010; Glaser, Bucher, Moergeli, Fauchere, Buechi, 2007; Kavanagh & Hershberger, 2005; Lang et al, 2011; Pector, 2004; Swanson Kane, Pearsall-Jones, Swanson, Croft, 2009). Fathers' views were not studied exclusively whereas mothers' views were exclusively sought in five studies (Abdel Razeq and Al-Gamal, 2018; Gold, Leon, Boggs, Sen, 2016; Lundqvist, Nilstun, Dykes, 2002; Richards, Graham, Embleton, Campbell, Rankin, 2015; Swanson, Pearsall-Jones, Hay, 2002). One study included an aunt who was the main carer of the deceased child. None of the selected studies included adoptive parents, foster parents or other main carers that were not family members.

Table 2.4 Scoping review – participant characteristics (n=19)¹

Participant characteristics	Mothers only	Fathers only	Both parents	Range of family members	Health professionals
Number of studies	5	0	13	1	1

¹ One paper had both health professionals and parents

The research methods of included studies are presented in Table 2.5. As anticipated, qualitative methods were the most commonly used methodological approach in the included studies. Of the 19 papers included, 10 were qualitative studies (Abdel Razeq and Al-Gamal, 2018; Abraham and Hendricks, 2017; Armentrout, 2007; Branchett and Stretton, 2012; Currie et al, 2016; Einaudi et al, 2010; Kavanaugh and Herschberger, 2005; Lundqvist et al, 2002; Lang et al, 2011; Richards et al, 2015); three were quantitative studies (Aho et al, 2019; Gold et al, 2016; Robertson et al, 2011); and there were six mixed methods studies (Baughcum et al, 2017; Brosig et al, 2007; Glaser et al, 2007; Pector, 2004; Swanson et al, 2009; Swanson et al, 2002). The research approaches in the qualitative studies were: descriptive designs (Abraham and Hendricks, 2017; Branchett and Stretton, 2012; Currie et al, 2016; Lang et al, 2011; Einaudi et al, 2010; Richards et al, 2015), grounded theory (Armentrout, 2007) and phenomenology (Abdel Razeq and Al-Gamal, 2018; Kavanaugh and Herschberger, 2005; Lundqvist et al, 2002). A purposive sampling strategy was used to select potential participants in 16 studies (Abdel Razeq and Al-Gamal, 2018; Abraham and Hendricks, 2017; Aho et al, 2018; Baughcum et al, 2017; Brosig et al, 2007; Currie et al, 2016; Einaudi et al, 2010; Glaser et al, 2007; Kavanaugh and Herschberger, 2005; Lang et al, 2011; Lundqvist et al, 2002; Pector, 2004; Richards et al, 2015; Swanson et al, 2009; Swanson et al, 2002); one study used theoretical sampling (Armentrout, 2007), one study used random sampling for their control population only (Gold et al, 2016), and two studies did not describe their sampling strategy (Robertson et al, 2011; Branchett and Stretton, 2012).

Table 2.5 Scoping review - search methods (n=19)

Research Method	Quantitative methods	Mixed Methods	Qualitative methods
Number of studies	3	6	10

The data collection methods used in the scoping review studies are presented in Table 2.6. Some studies used more than one data collection method. The purpose of reporting on data collection methods within this review was to consider what methods worked and were appropriate in the context of eliciting participant experiences in this challenging research area. Data collection methods included nine questionnaires or survey instruments, some of which were postal surveys and some were self-report

questionnaires used in a face-to-face setting (Aho et al, 2018; Baughcum et al, 2017; Brosig et al 2007; Glaser et al, 2007; Gold et al, 2016; Pector, 2004; Robertson et al, 2011; Swanson et al, 2009; Swanson et al, 2002); interviews were undertaken in thirteen studies (Abdel Razeq and Al-Gamal, 2018; Abraham and Hendricks, 2017; Armentrout, 2007; Baughcum et al, 2017; Brosig et al 2007; Currie et al, 2016; Glaser et al, 2007; Kavanaugh and Herschberger, 2005; Lang et al, 2011; Lundqvist et al, 2002; Richards et al, 2015; Swanson et al, 2009; Swanson et al, 2002); the delphi method was used in one study (Einaudi et al, 2010) and questions in an online community were used by one study (Branchett and Stretton, 2012). None of the studies included used an ethnographic study design, but one author stated that it used ethnographic aspects in their data collection with 'temporary field stays and minimal observation' (Abraham and Hendricks, 2017 p.2101). It could be argued that an observational approach to researching parents' experiences of end of life or grief is not a practical or sensitive approach. Interviewing as the most common method used for data collection is unsurprising as the flexibility of the interview enables the parents to share their experiences and disclose the amount of information they choose.

Table 2.6 Scoping review - data collection methods (n=19)¹

Data Collection Method	Interview	Survey or Questionnaire	Online Qualitative Questions	Delphi Survey
Number of studies	13	9	1	1

¹ Six studies used multiple data collection methods

The data analysis methods used for included studies are presented in Table 2.7. Qualitative thematic analysis methods were used in four studies (Branchett and Stretton, 2012; Brosig, 2007; Einaudi et al, 2010; Richards et al, 2015) and content analysis was undertaken in five studies (Abraham and Hendricks, 2017; Baughcum et al, 2017; Currie et al, 2016; Glaser et al, 2007; Lang et al, 2011). Three studies used phenomenological analysis methods, including both descriptive and hermeneutic approaches (Abdel Razeq and Al-Gamal, 2018; Kavanaugh and Herschberger, 2005; Lundqvist et al, 2002). An ethical analysis, where parents' responses were analysed to establish how practicality and ethics of care could be

improved, was used in one study (Einaudi et al, 2010), however the details of this type of analysis were not explained. A modification of Eave's grounded theory method was used for analysis in one study (Pector, 2004) and the constant comparison method in another grounded theory study (Armentrout, 2007). Finally, for the quantitative methods of analysis, both quantitative and mixed methods studies used descriptive statistics in nine of the studies (Aho et al, 2018; Baughcum et al, 2017; Brosig et al, 2007; Glaser et al, 2007; Gold et al, 2016; Pector, 2008; Robertson et al, 2011; Swanson et al, 2002 and Swanson, 2009). In two of the mixed method studies, the qualitative data analysis methods were not described (Swanson et al, 2002; Swanson et al, 2009).

Table 2.7 Scoping review - data analysis methods (n=19)¹

Data Analysis	Stats	Phenomenology	Thematic	GT	Content	Others²
No of studies	9	3	4	2	5	4

¹ dual methods of data analysis used for some studies

² others – ethical and context analysis and two qualitative analysis methods not described

All the studies focused on families whose babies died in the hospital setting or health professionals from the hospital setting. Neonatal palliative and end of life care is increasingly moving into the community setting (hospice or home) because families are increasingly being empowered to express their preferred place of death for their baby. Currently, there is no data available for how many neonates die in hospice or home settings across the UK, however some children's hospices now have a neonatal specialist nurse to facilitate this work and safe transfer into the setting. None of the studies represented community settings, therefore, the evidence in this scoping review represents the experiences of parents in the hospital setting only.

Two broad headings that relate to the review questions will be used to summarise the key finding from the studies reviewed: first, the impact on parents' lives after the death of their baby or child and second, studies that focus on support strategies and their effectiveness.

2.6.2 Impact on parents' lives after the death of their baby

This section aims to answer the first review question namely 'What is the impact on parents' lives following the death of their baby?' Many of the studies in this scoping review reflected the narratives of deep sadness experienced by parents both at the end of life and after the death of their baby (Abdel Razeq and Al-Gamal, 2018; Glaser et al, 2007; Kavanaugh and Herschberger, 2005; Richards et al, 2015). A consistent finding across included studies was that the nature of caregiving at the end of life impacted both positively and negatively on parents' emotions (Abraham and Hendricks, 2017; Armentrout, 2007; Baughcum et al, 2017; Einaudi et al, 2010; Lang et al, 2011; Lundqvist et al, 2002; Pector, 2004; Richards et al, 2015).

Parents' negative experiences of care delivery were highlighted. The experience of separation from their baby at birth had a negative impact on parents, but is not preventable due to the condition of their baby, and was intensified for mothers who underwent a caesarean section (Abraham and Hendricks, 2017). In these situations, fathers experienced significant worry about their spouse's health alongside their baby's fragility and spent time back and forth between their baby and partner (Glaser et al, 2007). Parents also experienced separation from their baby while being alongside them in the NICU because of the barriers of an incubator and equipment. Parents longed for some of the tactile experiences their peers were able to undertake but because their baby was too sick, they did not get to hold or have skin-to-skin contact with their baby; this prompted a sense of loss (Abraham and Hendricks, 2017).

Some studies highlighted that the negative attitudes from and actions by health professionals, such as an insensitive communication styles and not listening to parents' concerns add to parental distress (Currie et al, 2016; Einaudi et al, 2010; Lang et al, 2011; Lundqvist et al, 2002; Pector, 2004). Discontinuity of care and a lack of continuity of information were highlighted as hindering parents' ability to develop a trusting relationship with health professionals and added to parents' anxiety (Richards et al, 2015).

In some instances, end of life care had a negative impact on parents. For example, parents being coerced or informed that it was important to hold their baby during death, when parents did not want this experience (Lundqvist et al, 2002). Parents'

perceived that health professionals were judging them and that their opinions, feelings and decisions were not valued. This experience affected the development and/or maintenance of effective therapeutic relationships with a lack of trust and an unwillingness of parents to share their true feelings. Ultimately, these experiences had potential to have a profound effect on parents' memories of the death of their baby (Lundqvist et al, 2002). A lack of respect for parental involvement in decision-making at the end of life influenced parents' ongoing grief. Parents described these experiences as a 'violation' of their parental role, leading to helplessness and despondency (Lundqvist et al, 2002).

Health professionals' reactions to a baby death had the potential to impact on parents' emotions, both immediately after the bereavement and on-going during the grieving process (Einaudi et al, 2010; Lang et al, 2011). Parents reported that in some instances, health professionals minimised the significance of the death of their baby. This was manifested in the way professionals approached dealing with the death as an isolated clinical event only, seemingly devoid of emotional connection and compassion (Lang et al, 2011). Although this may be one way that health professionals cope with death, parents interpreted this behaviour as a signal that they were not expected to be deeply affected by their baby's death. At times, parents identified avoidance behaviours from professionals, such as a doctor avoiding contact with parents once death has been pronounced (Einaudi et al, 2010). For some, these experiences resulted in parents not wishing to engage with health professionals later in their grief journey when they were invited to attend the hospital for a follow-up appointment. The way in which care was organised also had the potential to impact on parents' experiences and emotions (Einaudi et al, 2010).

Across many of the studies reviewed, the baby had been in hospital or known to the hospital staff for a significant time prior to death. This longevity and depth of the therapeutic relationship and the consequent abrupt ending of this relationship appeared to add to parents' loss and grief (Baughcum et al, 2017; Branchett & Stretton, 2012). Once their baby had died, a feeling of loneliness and sometimes abandonment by health professionals confounded parents' loss; parents had to leave the hospital setting, their baby and for some parents, what had been their 'home' for many weeks or months. Some parents identified that this sense of abandonment was synonymous with health professionals being able 'get on with life' whilst they could

not (Einaudi et al, 2010). This detachment has been theorised as a 'secondary loss', compounding parents' sense of isolation (Einaudi et al, 2010).

While negative encounters of care and communication were at the fore of many parents' experiences across included studies, some studies reported parents' accounts of positive caring behaviours. Empathetic caring behaviours included: being genuine in interactions, health professionals always using the baby's name and a compassionate approach to communication and daily care (Baughcum et al, 2017; Currie et al, 2016; Richards et al, 2015; Pector, 2004). One study highlighted parents' experiences of nurses' support by being a lifeline of communication in the NICU, a comforting presence and preparing family for end of life (Currie et al, 2016). Some parents valued expressions of emotion from health professionals when their baby died as this appeared to acknowledge their own grief and reinforced how valued their baby was to them, but also to the health professionals (Lundqvist et al, 2002). Parents reflected on the emotion and empathy from health professionals, weeks and months after their baby's death and stated that the care from these individuals was very good (Lundqvist et al, 2002; Pector, 2004).

Parents reported mixed emotions, for example one study reported on mothers' whose babies died felt simultaneously being empowered and feeling powerless (Lundqvist et al, 2002). Empathetic care led to feeling empowered and conversely being ignored or coerced into care decisions by health professionals led to a sense of powerlessness. These experiences are likely to have an impact on mothers' grief experiences as they have to live with and potentially accept their contribution to end of life decision-making. Health professionals' care and attitudes at the end of life have the potential to influence parental grief patterns. Later deep reflection on events at the end of life in order to establish meaning is common in grieving patterns (Neimeyer, 2000). Parents described communication styles and caring behaviours as means of establishing the meaning of emotions and negative experiences can complicate parental grief (Lundqvist et al, 2002; Einaudi et al, 2010; Lang et al, 2011; Richards et al, 2015; Pector, 2004).

Some studies described parents' grief as a 'disenfranchised' grief experience, where the grief experience is not acknowledged by society or others (Attig, 2004), which occurred in a range of contexts including within the marriage, within the family, when

interacting with the wider community and when interacting with health professionals (Lang et al, 2011, Swanson et al, 2002). The studies that also included some participants with pregnancy loss highlighted the relevance of disenfranchised grief for these parents (Lang et al, 2011; Swanson et al, 2002), which was reinforced by health professionals referring to the baby's body as 'remains' (Lang et al, 2011). Disenfranchised grief experiences were also related to neonatal deaths where findings identified the sense of isolation that parents felt after the death of their baby, and lack of opportunity to discuss their feelings and emotions (Lang et al, 2011; Swanson et al, 2009).

Significant challenges were highlighted for parents of multiple babies when one of their babies died. In these studies, the phrase 'multiple' was used to describe any multiple birth other than twins, such as triplets or quadruplets. Some of the studies included parents where all of their multiples had died and those parents who had both a surviving and deceased twin. Those parents who had a surviving twin or multiple described a life that included grief, joy and guilt (Swanson et al, 2002, Pector, 2004). Parents described difficulties with attachment to the surviving twin or multiple (Pector, 2004). Some of the studies described parents who had actively resisted attachment with the surviving twin or multiple because of fear of the death of the surviving baby and the resemblance of the survivor to the deceased baby (Pector, 2004). These emotions and feelings where a baby resembled their brother or sister had the potential for long term impact on their grief and mourning experiences. As the surviving baby or child grows, the resemblance or reminder of how the deceased baby would have looked does not abate.

Across studies, both mothers and fathers participated and while the aims of the studies were not necessarily to compare gender experiences, the authors highlighted some differences in their experiences. Two studies that included multiple births reported mothers perceived their early grief to be more intense and painful than fathers and more long-lasting (Swanson et al, 2002, Swanson et al, 2009). In addition, self-reported depression scales were noted to be different between the mothers and fathers, with fathers reporting relatively low levels of both current and retrospective depression (Swanson et al, 2009). In contrast, mothers described low current levels of depression, but high levels of retrospective depression. Research using the Dual Process Model (DPM) of coping with bereavement suggests there is a

difference in gender experiences of grief work but that different experiences do not necessarily denote a more painful experience for one gender over another (Stroebe & Stroebe, 1983).

2.6.3 Support strategies offered and their effectiveness

This section focuses on the second review question, 'What support strategies are parents offered after the death of their baby and how effective are these strategies?' Support strategies used by parents started in the end of life period and continued in the grief journey. The creation of memories in palliative and end of life phases of neonatal care helped parents with the bereavement event and mourning experience (Abraham and Hendricks, 2017; Armentrout, 2007; Baughcum et al, 2017; Branchett & Stretton, 2012; Currie et al, 2016).

Across study findings, parents identified a lack of availability of support strategies, or when support was available, it was not always offered immediately after the death and was not always offered later in the grieving process (Abdel Razeq and Al-Gamal, 2018; Branchett and Stretton, 2012; Brosig et al, 2007; Kavanaugh and Hershberger, 2005; Lundqvist et al, 2002; Pector, 2004; Robertson et al, 2011). The optimum timing of support and therapeutic intervention was reported as being difficult to predict when individuals have different needs at different times (Einaudi et al, 2010).

Studies highlighted that support was provided by health, social and spiritual care professionals, and from peers, family and friends (Abdel Razeq and Al-Gamal, 2018; Brosig et al, 2007; Kavanaugh and Hershberger, 2005; Lundqvist et al, 2002; Pector, 2004; Swanson et al, 2009). Across studies individual participant perceptions of support was variable within and across care settings (Branchett and Stretton, 2012; Einaudi et al, 2010; Kavanaugh and Hershberger, 2005; Lang et al, 2011; Lundqvist et al, 2002). Support was reported to range from no support, to support from professionals, peers, friends and families.

One study highlighted that for some parents spiritual support in the NICU was important (Currie et al, 2016). Some parents searched for meaning in their loss through their faith and spiritual beliefs after their baby's death and rationalised their loss in relation to the 'blessing' of having their baby for a short period of time or their baby was no longer 'suffering' or in pain (Abdel Razeq and Al-Gamal, 2018;

Armentrout, 2007; Swanson et al 2009). This was a strategy to cope with their emotional work and the physical absence of their baby. One study found faith to be a prevalent component in the daily lives of parents and that they thought about being reunited with their baby one day (Armentrout (2007). Drawing on spiritual beliefs and or faith to for coping, gave parents hope and comfort.

Post-traumatic stress disorder (PTSD) and depression were symptoms that were identified as prevalent in parents bereaved in the NICU (Aho et al, 2018; Gold et al, 2016). Bereaved mothers were four times as likely to have PTSD and seven times as likely to have depression as non-bereaved mothers (Gold et al, 2016). However, data is not available to compare fathers' PTSD and depression scores to mothers' scores. Peer support offered through a family weekend was not found to have any statistical significance in the change in parents' PTSD and depression scores. However, parents valued and acknowledged that the peer support experienced during the family weekend had been supportive, and mothers found this mode of support more helpful than fathers did (Aho et al, 2018). Parents who were pregnant during data collection were less likely to screen positively for depression and anxiety (Gold et al, 2016).

Communicating and sharing with other parents who had experienced the death of a baby was perceived to lead to positive outcomes such as not feeling alone in their grief and having others who understood their situation, in two studies (Aho et al, 2018; Brosig et al, 2007). Bereavement support groups were found to be generally helpful in several studies (Brosig et al, 2007; Pector, 2004; Swanson et al, 2002). However, one study reported bereavement support groups did not meet the needs of all parents (Brosig et al, 2007). Some parents described elements of disenfranchised grief from peers in support groups who had lost older children, and these parents perceived that judgements were made, such as some parents perceiving their loss as being more significant than others (Brosig et al, 2007). Other parents felt their situation to be unique and poorly understood (Pector, 2004). This may explain why accessing bereavement support groups is not described in more of the studies in this review.

In some studies, psychological support was reported to be available but similarly to bereavement support groups, not widely utilised. Some parents explained their

reluctance to engage with support offered was influenced by the long period of denial and described a greater need for support some months, or even years later (Einaudi et al, 2010; Glaser et al, 2007). Some mothers described experiencing a 'social desert' after two months, when initial family support had subsided and suggested that this would be an appropriate time for professional support systems to be offered (Einaudi et al, 2010). Some parents identified that counselling or supportive services should not only be offered in the initial bereavement period but extend in the months and years following as psychological distress is long-lasting (Glaser et al, 2007).

Some parents highlighted the need for distraction in daily life and a desire to be moving forward (Abdel Razeq and Al-Gamal, 2018) and fathers described diversion behaviours more than mothers in one study (Kavanagh and Herschberger, 2005). Future pregnancy was described by some parents and the fulfilment of the need for another baby brought happiness and healing for some (Abdel Razeq and Al-Gamal, 2018; Glaser et al, 2007; Kavanagh and Herschberger, 2005). However, the majority of studies in this review did not describe parents' desires about moving forward in life.

Encountering difficult situations in parents' early grief, such as, celebrating special days and holidays, for example, Christmas, birthdays or mother's and father's day was highlighted in one study (Kavanagh & Hershberger, 2005). Some situations proved to be a particular challenge to mothers, such as, being around pregnant women and baby showers. While the timing of some of the difficult situations are predictable, such as holidays, other 'trigger' situations were found to be unavoidable. Many of these difficult situations differ between individuals and this requires the parent themselves to raise their need for support at that time. These trigger situations appeared to initiate deeper grief pangs and could be confounded by a lack of sensitivity from those people around the parent, often indicating disenfranchisement.

2.7 Discussion

Several key findings have emerged from this review. First, positive and negative caring experiences can have a significant impact on parents' emotions. Further, the impact of leaving the supportive nature of the hospital and its staff has a secondary loss impact on parents. Second, although strategies in place in some care settings provide psychological support to bereaved parents, each individual parent, even

within the same family, will have differing needs at different times in their grief journey. Support groups, bereavement visits, counselling and memory boxes may facilitate parental grief, but there is little empirical evidence that has measured the effectiveness of professional therapeutic interventions in this setting. Third, there is limited evidence on what kinds of therapeutic interventions may be suitable for parents at different stages in their grief journey. There is little recognition within this body of evidence, as to what degree of importance family, friends, peer and spiritual support are and how vital this might be to resilience and life functioning. Equally, there is little evidence of optimum timing for therapeutic interventions during parents' grief journeys.

In the UK, 99% of NICUs provided parents with photographs of their baby and up to 68% of units provided parents with a memory box (Robertson et al, 2011). Nurses described neonatal end of life care as having a key focus on memory making in collaboration with parents. Parents wanted pictures of their live baby, clear of equipment and any items that had been worn by their baby. Parents were also appreciative of the time taken to create keepsakes (Kavanagh & Hershberger, 2005). Parents felt that nurses took the initiative during this time period, presenting options for parents and with the creative and delicate process of making memories. It was considered a precious time that produced a tangible collection of memories and objects to behold. Some parents accounts described regret of not doing more, being involved more at this time (Armentrout, 2007; Baughcum et al, 2017). This highlights a potential need for nurses to be more empowering of the parental role at this stage, offering options and being alongside parents in this difficult time.

Creating memories is not just a short-term comfort and support to families in the early bereavement period but may also facilitate the continuing bonds with their baby as they grieve and reflect on the life events that they would have shared with their child in later life (Klass et al, 1996). This strategy for support is significant because death in the neonatal period means that time is limited to create memories, the memories created are finite, and so they are incredibly precious. It is notable that so many studies in the review highlighted the importance of memory-making and mementoes.

This review highlighted a lack of support readiness and availability for some parents during and after a neonatal death. Not only was this described internationally across

several studies (Kavanagh and Herschberger, 2005; Richards et al, 2015), but also in the UK (Robertson et al, 2011). What parents and health professionals consider supportive can also differ. There is a potential disconnection between support that is offered being perceived by most parents as helpful, for example, the six-week follow-up appointment. This emphasises the need for timely, individualised assessment and support for all parents (DH, 2008a, DH, 2009). However, parents should leave the hospital setting with information on how and when support will be provided and how they can access it.

Depression is widely accepted as a symptom of grief, particularly when the loss relates to a child however, PTSD is not recognised by professionals in NICU as a likely factor arising from these experiences. Two studies highlighted the prevalence of psychological trauma in parents bereaved in the neonatal setting and that it is a potentially long-lasting symptom (Aho et al, 2017; Gold et al, 2016). Professional education and awareness are needed about PTSD with focus on high quality caring experiences in NICU that do not increase the likelihood of PTSD and support systems in place to assess and treat the symptoms should they arise.

No studies from developing countries were included and this may reflect that palliative and end of life care for neonates is only beginning to be recognised as a priority in some developing countries. Care priorities and therefore research priorities for neonates in developing countries are focused, by necessity, on cause of death and reduction of mortality rates (Lawn et al, 2005). Low and middle-income countries account for 99% of neonatal deaths, yet little progress has been made with lowering the mortality rate (Lawn et al, 2005). Whilst it is justified that neonatal research priorities are directed to other significant matters than parental grief and support, it could be argued that with such high death rates in developing countries, parental need is high.

2.8 Review limitations

The review has several limitations. First, while every effort was made to include all studies relating to the topic focus, the search was restrained by the databases available at the institution the review was undertaken, and a wider range of databases may have generated additional studies. However, the databases used, index a wide range of health and social sciences journals. Second, undertaking a

systematic review, which is associated with integrative data synthesis, may have resulted in a greater theoretical depth to the discussion, but this is not the purpose of a scoping review and as previously identified, a systematic review was not the appropriate strategy to meet the review aim. In addition, guidance for scoping review methodology suggests a two-person iterative approach to study selection. For this scoping review, as part of a PhD programme, this was not appropriate. However, it could be argued that a two-person approach to study selection would have yielded slightly different results and a more robust strategy.

2.9 Gaps in the literature

Whilst internationally there are some good examples of psychological support strategies offered to bereaved parents following a neonatal death, these examples are not available to all parents. There was little evidence of what support was available from family and friends and how useful that was. The evidence measuring therapeutic interventions related to a peer support weekend for bereaved parents experiencing PTSD and depression. More common support strategies such as bereavement nurses and counselling were not discussed or evaluated in the literature reviewed. In the UK, more work is needed to ascertain the parental perspective of current and future care provision during and following the death of a baby to yield contemporaneous understanding. In addition, the experiences of families whose baby died in the home or hospice setting is a research priority because parents are increasingly being offered choices about their baby's preferred place of death. Furthermore, research focusing on the effectiveness of current therapeutic interventions across both the National Health Service (NHS) and third sector care settings is needed.

2.10 Summary

This scoping review found that the way care is delivered, health professional attitudes and the way they communicated with parents at the end of the baby's life impacted on parents' emotions. The complication of the death of a twin or multiple siblings resulted in disenfranchisement, which then had an impact on parents' grief experiences. Support strategies identified included counselling, peer support groups, and follow-up appointments at the hospital. Some parents were not offered any support after their baby's death, and the uptake for support groups and psychological

support in general was variable. To date, the focus of research has been on the care for the neonate and their parents during the last days of life. This timeframe needs extending into the grieving period and to include psychological aspects of care. Informed thinking, understanding of parents' perceptions and the support needs at the end of their baby's life and after their baby's death could inform future care and service delivery to ensure the health and wellbeing of parents affected by this life-changing experience. There is a paucity of research about parents' experiences of neonatal death and bereavement support, particularly in the UK. The study undertaken for this PhD thesis, has the potential to add unique knowledge and evidence not only to the UK care setting but also to wider care settings, particularly in some European countries, where healthcare systems and care delivery are similar.

Chapter 3 – Ethical considerations

3.1 Introduction

This chapter presents the ethical considerations in relation to undertaking a study exploring the experiences of bereaved parents. A discrete chapter was relevant because ethical considerations were a central component for deliberation throughout the study because of the sensitivity required when approaching and collecting data from participants that have experienced a bereavement (Stroebe, Stroebe and Schut, 2003). In addition to gaining informed consent, considering confidentiality and anonymity, and ensuring data protection and data safety, two significant ethical problems are presented. The first problem was whether undertaking research with bereaved participants was ethical and justifiable and the need to keep participants emotionally and psychologically safe was considered. The second problem was my own psychological safety and well-being and the strategies implemented to minimise the actual and potential risks. A risk-based approach to assess, plan and strategise the ethical issues was used (Long, 2007).

3.2 Researching with bereaved participants

Undertaking research with bereaved participants, particularly after the death of a baby, posed several concerns which were considered when designing the study. Literature about other researchers' experiences was reviewed, including methods and ethical approaches to palliative, end of life or bereavement research. This informal review identified common approaches to undertaking research with participants in similar situations (Addington-Hall, 2002; Brosig, 2007; Casaret, Knebel and Helmers, 2003; Einaudi et al, 2010; Kavanaugh et al, 2005; Lang et al, 2011; Lundqvist et al, 2002; Strobe et al, 2003; Swanson et al, 2009; Swanson et al, 2002). Whilst a wide range of experiences and approaches were reported, a timely and sensitive approach to recruitment and data collection were highlighted as ethical issues.

A search for national guidance on palliative, end of life and bereavement research highlighted a lack of direction, with only a brief reference to undertaking research

sensitively in an adult end of life strategy document (DH, 2008b). The Scottish Partnership for Palliative Care (SPPC) produced a guidance document on palliative care research, however the guidance provides general information with a focus on methods and limited guidance on the ethical challenges and how these might be addressed (SPPC, 2011). The lack of explicit UK guidance on researching in sensitive end of life and bereavement situations prompted a search for guidance in similarly developed healthcare settings. A US framework was found to be useful (Casaret et al, 2003) and was adapted to a UK healthcare and research ethics context (Figure 3.1). The framework was used as a reference to guide each stage of the research process in this study.

Maximising benefits, minimising risk and burdens	
1	Research committees should include members familiar with end of life
2	Support/rescue strategies in place
3	Confidentiality issues need to be anticipated and strategies in place
4	Interviews need not cause distress, research is crucial, therefore strategies to manage distress should be in place
5	Appropriate time frames need to be adopted
6	Research activities should not have a direct effect on care

Figure 3.1 An ethical approach to research design in palliative care Adapted from Casaret et al (2003)

The framework has some limitations. The first recommendation of the framework is that when reviewing study proposals with an end of life focus, research ethics committee should include expertise in end of life care. The National Health Service Research Ethics Committee (NHS REC) did not have a member that specifically specialised in end of life care. However, many of the professional members of the committee, including the Chair of the committee, were clinicians or nurses with knowledge and experience in palliative and end of life care.

Reflection point 3.1: the case for neonatal bereavement research

I was asked to attend the regional NHS REC for to discuss my application for approval to undertake the study. A lay member of the panel asked whether I should be interviewing a parent after the death of a baby. I gave my answer rationalising the potential risks to a parent and benefits for future clinical practice. The lay member persisted his point, at which point the chair person and another member of the panel intervened and supported the points I made. The application was successful.

While the framework by Casaret et al (2007) was useful especially in preparing the application the main ethical guide relevant to this study was the risk-based approach by Long and Johnson (2007). This approach to ethical practice allowed for reflexivity and a fluid and adaptable approach to the challenges that arose whilst undertaking this research. Using the risk-based approach demonstrated that some of the challenges faced in this research were reliant on my own practice in ethical decision-making and integrity under pressure (Fallon and Long, 2007). I realised that although my NHS REC application was approved, that did not mean that the research would be ethical unless I applied the processes outlined in my application and utilised a risk-based approach to each of the decisions and challenges that arose. The discussions that follow on participant well-being and researcher well-being, demonstrate how I used this risk-based approach to decision-making and ultimately the research process.

3.2.1 Participant vulnerabilities and potential risks

The following section addresses participant vulnerabilities and the potential risks to participants' emotional wellbeing due to being part of the study. The issue of the timing of contacting potential participants, ensuring that timing was sensitive to their loss while ensuring that the research aim and objectives were met is considered. Finally, the key strategies used to minimize the risks to participants, including PPI (patient and public involvement) in the development stage of the research are outlined.

The key ethical considerations of this study related to the sensitive and emotive nature of the issues being researched. Bereavement is a topic that is considered a sensitive research field because participants are inherently vulnerable in their grief (Addington-Hall, Bruera, Higginson and Payne, 2007; Alty and Rodham, 1998; Lee, 1993). This is further emphasised when considering research into child and neonatal bereavement (Parkes and Prigerson, 2010). Bereavement research including exploration of end of life experiences is intrusive and possibly emotionally threatening to some, however it is an accepted and valued area of research in a range of professional fields (Addington-Hall et al, 2007; Chan, Teram and Shaw, 2015; Wiegand, Norton, Baggs, 2008). Furthermore, bereavement research is emotionally charged for both participant and researcher (Lee, 1993).

A potential concern from a researcher perspective, NHS REC expectations and anticipated parents' position, was the 'emotional charge' arising from discussing their baby's end of life care. Participants' own grief experience might be extremely challenging for some parents, threatening their already tenuous well-being. An additional concern was that this research could pose a risk to researcher well-being due to the emotional burden arising from interacting with bereaved participants and listening to their difficult narratives. Although bereavement and grief are often considered a private matter, this sensitive research topic should be explored, as evidence is crucial to improving the quality of holistic care at the end of life and after bereavement.

The researchers' role is to minimise threats to participants' well-being and to employ strategies to ensure the psychological and physical safety of participants. It has been suggested that qualitative research through unstructured interviews on sensitive topics are less of a risk to participants than a clinical trial, because the participants retain more control over the process in the qualitative research setting (Corbin and Morse, 2003). However, this underestimates the emotional journey that occurs when sharing deeply personal experiences (Stroebe et al, 2003). The initial consideration for the doctoral study in this thesis was whether research undertaken with bereaved parents about their experiences could be justified and whether the risks for psychological safety of participants could be mitigated. This means that the research should ideally not harm any participant or that any harm caused should not be disproportionate to any new knowledge gained.

As a registered nurse, there were additional professional considerations that shaped the ethical approach to the study, the Nursing and Midwifery Council (NMC) Code, which must be upheld in all the facets of my role as a nurse, including that of a researcher (NMC, 2018). There have been three iterations of the NMC code for professional practice in use during the duration of this study, however all three are similar in intent particularly the 2015 and 2018 revisions. Two parts were particularly significant: NMC Code 17.1 "Take all reasonable steps to protect people who are vulnerable or at risk from harm, neglect or abuse" (NMC, 2018 p.15). Additionally, 19.4 "take all reasonable personal precautions necessary to avoid any potential health risks to colleagues, people receiving care and the public" directs the nurse to ensure that risk is minimised and mitigated (NMC, 2018 p.17). One of the tenets of the nursing profession is not to cause harm to patients and this principle is significant to the research being undertaken for this thesis.

In addition to the sensitive nature of the research, potential participants were vulnerable because of their past and present highly emotional experiences, and the ongoing impact of those experiences on their own and their families' lives and future expectations (Kavanaugh, Moro, Savage & Mehendale, 2006). Vulnerability has been conceptualised to identify groups, populations and behaviours in context of what puts these groups at higher risk (Purdy, 2004). Vulnerability can be defined with some key terms such as, unprotected, undefended, and sensitive or being susceptible or at risk of harm (Purdy, 2004). The participants for this study would be considered vulnerable

due to their experiences (Kavanaugh et al, 2006; Stroebe et al, 2003). For all these reasons, when ethical approval was sought consideration was given primarily to the prospective participants but also to researcher well-being.

3.2.2 Time frames for research

There are significant differences in opinions regarding when to invite potential participants to participate in research studies after the bereavement event (Addington-Hall et al, 2007; Lee, 1993; Parkes and Prigerson, 2010; Stroebe, Stroebe, Schut, 2003). This study required participants with a relatively recent bereavement experience in order that study findings could influence contemporary practice and identify support needs at the end of life and after bereavement. How individuals feel about being contacted post-bereavement for research purposes will be subjective and unique to the individual because of differences in their current grief journeys and readiness to talk about their experiences. Capturing data too close to the death of the baby may have hindered parents' experiences through the early grieving process. Conversely, if participants were a long time post-bereavement, memories could potentially deteriorate. Whilst there is a need to elicit data close to the bereavement event, some researchers suggest that individuals can recall significant memories relevant to them despite the passing of time because they replay events (Elmir, Schmied, Jackson, Wilkes, 2011; Levine and Safer, 2002). Despite this ability to recall memories long after the event, a decision was made to invite participants within 24 months following the baby's death to capture experiences that are applicable to current care. The rationale for this decision is discussed below.

Studies investigating bereaved participants' experiences presented in Chapter 2 were evaluated in relation to timeframes between death and data collection. Not all studies stated the time frames for recruitment and data collection. For those that included a time frame this ranged from 3 months to 11.8 years (Figure 3.2). Studies evaluated on the broader research on bereavement outlined in Chapter 1, were also reviewed in relation to timeframes between death and data collection (Figure 3.1).

Authors	Time after death data collected
Abdel Razeq and Al-Gamal (2018)	3-18 months
Baughcum et al (2017)	3 months – 5 years
Brosig et al (2007)	6-24 months
Currie et al (2016)	After 15 months
Einaudi et al (2010)	3 months – 10 years
Glaser et al (2007)	3.5 – 6.5 years
Gold et al (2016)	9 months
Kavanagh et al (2005)	Within 4 months
Lang et al (2011)	2-13 months
Lundqvist et al (2002)	14-32 months
Richards et al (2015)	6 months – 2 years
Swanson et al (2009)	Average time 9.12 years
Swanson et al (2002)	Average time 11.8 years

Figure 3.2 Post-bereavement contact timeframes in the selected literature review papers from Chapter 2

Authors	Time after death data collected
Stroebe et al, 2002	4-25 months
Wijngaards-deMeij et al, 2005	6-20 months
Schut and Stroebe, 2005	6-24 months
Aho et al, 2006	2.5-24 months
Wijngaards-de Meij et al, 2008	6-20 months
Nikkola et al, 2013	2-6 weeks
Harper et al, 2014	2-59 months
Stroebe et al, 2014	4-20 months

Figure 3.3 Post-bereavement contact time frames – other significant studies

There was significant variability in the post-bereavement timeframes for contacting participants, as presented in Figures 3.2 and 3.3. However, there seemed to be some consistency in 4-6 months post-bereavement contact initiation, and this influenced the decision about when to contact potential participants for this study. Additionally, Strobe, Strobe and Schut, viewed as expert researchers in the field of bereavement research, studies involved contact and data collection from participants at six months post-bereavement (Stroebe et al, 2014; Stroebe et al, 2003; Stroebe et

al, 2002; Stroebe et al, 2001; Stroebe et al, 1999). The optimum approach to deciding when to contact participants when topics are sensitive is to undertake pilot interviews at different time points and ask participants when they would have felt comfortable being approached (Stroebe et al, 2003). However, this was not suitable for this doctoral study because of the small sample size and the timeframes required for meeting the requirements of the programme and NHS REC conditions.

After consultation with practitioners working in the NICUs and discussion of timeframes used by other bereavement researchers, it was decided that parents would be included in the study only after six months following the death of their baby extending to a maximum of two years after the death. It was assumed that if prospective participants were not comfortable being approached, they would not reply to study information. Additionally, neither of the NICUs sending recruitment packs on behalf of the researcher received any feedback about being approached to participate or the timing of invitations.

3.2.3 Strategies to optimise participant well-being

It was imperative that the potential for the interview to cause emotional distress was balanced against the potential to improve the caring experiences for other parents through this research. The NHS REC and the NHS R&D committees acknowledged that despite the potential vulnerabilities of participants and the sensitive subject matter, the research was justified and the processes and strategies in place to support participants were appropriate. Three strategies were adopted to ensure that risks were minimised, and support strategies were in place for all participants. The first strategy was to take care over the content of any written information that was sent to potential participants. This was facilitated by the second strategy to ensure participant safety, which was having a PPI reference group from the inception of the study. The group provided insider perspectives that were central to the development of the study. It included three parents of whom one parent had experienced a neonatal bereavement. Details related to the PPI and development of study materials are discussed in Chapter 5, Section 5.2.2.

The third strategy related to offering support during and after the interviews for all participants. It was recognised that participants might experience some emotional

distress arising from the personal stories that might emerge (Kavanaugh et al, 2006). Responding to parents who were emotional when describing distressing events was considered in advance of data collection (Clarke, 2006). Decisions about whether to encourage a topic, remain silent, to stop or to pause the interview were individual to each participant; where possible anticipating participant's needs was prioritised. My extensive experience and training as a bereavement support sister were crucial to being able to judge the changing emotional climate of each interview and to act accordingly. Balancing the need to elicit meaningful data that describe the parents' experiences accurately with being responsive to the sensitivity of the information being gathered and parents' emotions was considered. Breaks, tissues and refreshments were utilised if parents were emotional (Elmir et al, 2011). It was anticipated that for some parents the narrative would be upsetting, and parents were offered support in relation to choosing whether to pause, continue or discontinue the interview. Some participants chose breaks, having refreshments and smoking breaks. Stopping the interview was offered as an option; no participants wished to stop the interview completely, however, some welcomed a break when suggested to relieve the emotional tension from the difficult narrative in which they were involved.

Reflection point 3.2: how actual and potential distress was managed

All participants involved in the study were grieving and some degree of distress was expected. However, when distress for some parents appeared greater than anticipated, then strategies for relieving the distress within the interview were initiated. It was anticipated that some parents might have an increase in need for support after sharing their narrative.

Access to support from a variety of organisations and charities were signposted to all participants after the interview was concluded (Wiegand et al, 2008). The support information is presented in Appendix III, study materials. In addition, the researcher's contact details were provided to answer any queries about the interview, but it was explained sensitively but explicitly that this was not offered as a therapeutic intervention. None of the participants contacted me after the interview for advice or support.

3.2.3.1 Benefits of participation

Participants signed a consent form to indicate that they understood that there would be no benefit to them directly from taking part in the research. Nevertheless, it is widely documented that there are benefits from participation in qualitative research (Corbin and Morse, 2003; Hutchinson, Wilson and Wilson, 1994). This was evident in some of the interviews where participants revealed being relieved at being able to talk about aspects of their experiences for the first time. The potential benefits of participating in research of this nature are reported to be catharsis, self-acknowledgement, sense of purpose, self-awareness, empowerment, healing and providing a voice to the disenfranchised (Hutchinson et al, 1994)

Each of the potential benefits were relevant to participants in this study, however catharsis, self-acknowledgement, sense of purpose, empowerment and providing a voice to the disenfranchised were important. The opportunity for catharsis can arise from the opportunity of having a captive listener about a subject. This can facilitate the release of emotions kept inside and potential relief from emotional turmoil (Hutchinson et al, 1994; Kubler-Ross, 1969). Self-acknowledgement is defined as the feeling of validation as a human being: that their story has worth and value (Hutchinson et al, 1994). Listening to an individual's narrative not only offers potential validation of the experience but also legitimises the person's feelings. The ability to tell their own story potentially empowers participants, by allowing them to speak in their own voice with understanding and interpretation (Hutchinson et al, 1994). Disenfranchisement was explored in depth in chapter 1, and it is acknowledged that participants in this study may have been experiencing disenfranchised grief. It was an aim of this study to facilitate and empower the participants to voice their experience when they may have felt previously that they had no voice or right to voice their experience due to reactions from others (Doka, 1999; Hutchinson et al, 1994). Benefits from participation in qualitative research have been demonstrated through therapeutic transformation during the research process (Ortiz, 2001).

Participants may find that telling their story is not only therapeutic, but it can also offer healing and relief (Elmir et al, 2011). This seemed to be the case for several participants, and some expressed gratitude at having a captive listener and that it was good to talk about these issues. One parent said it was good to talk about some things she had never told anyone. Whilst this concept of catharsis in sensitive

research was not part of the research aim and objectives, it was expected that some participants might find a sense of relief in talking about their experiences.

3.2.4 Boundaries and reciprocity

There is a regulatory expectation to maintain clear boundaries professionally in the researcher-participant relationship (NMC, 2018; Council for Healthcare Regulatory Excellence, 2008). Providing clear boundaries through the researcher's behaviour, rapport-building, and explicit discussion of what and how the relationship will develop can facilitate an understanding of the researcher-participants relationship and manages future expectations. While, the relationship must be professional, there is a need to build rapport to develop a relationship with participants to ensure a successful interview and meaningful data elicitation. To develop rapport, an exchange of personal information is often required, and participants expect this relationship to be reciprocal. As participants share private and personal information, they may expect some information in return (Sivell, Prout, Hopewell-Kelly, Baillie, Byrne, Edwards, Harrop, Noble, Sampson and Nelson, 2015). 'Conversational intimacy' and an essence of trust is crucial for rapport building and disclosure of sensitive narrative (Corbin and Morse, 2003). For example, parents asked me if I was a mother, and I offered general information about being a mother to two children. That exchange of information seemed relevant to parents, in that I understood what it meant to be a parent and to love a child. Parents often wanted to probe my experience in neonatal care and bereavement support to ascertain if I understood the context of what they were saying. I expanded on anything participants wanted to know about my professional experience, however, I did not tell them which hospital I was previously employed in, so as not to hamper any disclosure. Some self-disclosure can foster a less intimidating environment and balance the power perception in the relationship, but it must be balanced against influencing participants' narratives (Elmir et al, 2011).

It is acceptable to give some information in exchange and foster an amount of reciprocal information. However, caution must be applied because participants may potentially make requests that go beyond professional boundaries of the researcher-participant relationship, and skill and sensitivity are required to maintain trust and rapport whilst being clear about relationship boundaries (Corbin and Morse, 2003). Considered decision-making is required to balance participant requests for

information alongside the prescribed ethical requirements of the study, professional regulatory requirements and the researcher's personal code of ethics (Corbin and Morse, 2003). These issues were some of the ways in which I employed a risk-based approach to ethical research practice, by decision-making 'in the moment' in a way that promoted the researcher-participant relationship, that also adhered to NHS REC governance but still showed compassion, advocacy and allowed for power balance between the two parties (Johnson, 2007).

3.3 Researcher well-being

Discussion about research that explores sensitive topics such as palliative, end of life and bereavement care tends to focus on the participant experience. This is appropriate and justified. However, it is logical to accept that there is a potential risk to researcher well-being too, yet there is a paucity of research exploring the impact or potential impact on the researcher of undertaking research on sensitive and emotive topics. The following section is an exploration of the current evidence base for researcher risk and well-being, alongside discussion of the strategies adopted to safeguard the researcher in this study.

The sensitive nature of this study had the potential for the researcher to be vulnerable to emotional overload (Butler, Copnell, Hall, 2017). The researcher not only has to manage the emotions of the participant, but they also need to manage their own emotions. There is a professional obligation to consider personal safety as the NMC Code states in 13.4 "Take account of your own personal safety, as well of the safety of the people in your care" (NMC, 2018, p13). My own previous engagement in bereavement work with families, together with the longevity of my previous clinical experience, meant that I had already developed strategies for coping with the emotional burden of working with bereaved parents. However, the projected time period for recruitment and data collection spanned two years, and the risk of burnout and secondary stress was a possibility. Burnout is characterised by physical, emotional and spiritual exhaustion, depersonalisation and a perceived reduction in personal accomplishment (Cummings, Singer, Hisaka, Benuto, 2018). Secondary stress has been defined as "the stress caused by the pressures placed on professionals who care for others in need" (Wicks, 2006, p. 14). Even though therapeutic care was not the purpose of the relationship, burnout and stress were

possible because of the researcher-participant relationship and the nature of narratives shared by the participants. If this study had a larger sample, it would have been prudent and necessary to have other researchers involved in data collection and transcription to prevent secondary trauma and burnout due to significant exposure to participant narrative (Kendall and Halliday, 2014). My role as researcher in this field was new, and previous bereavement work that I had undertaken was supported by regular clinical supervision, therefore strategies were necessary to ensure my psychological health and well-being (Butler et al, 2017)

Three strategies were utilised to deal with the potential and actual risks of undertaking this research for the researcher. First, regular appointments were negotiated and scheduled for clinical supervision with a registered counsellor with bereavement counselling experience. These appointments commenced at the start of data collection and were planned to continue until the end of data analysis. As the study progressed, it became clear that some further supervision was still needed beyond data analysis and this is discussed in next section. Second, reflective journaling facilitated engagement with emotions arising from data collection, transcription, data analysis and writing the thesis. Third, academic supervision provided pragmatic guidance, reassurance and direction. In addition, academic supervision allowed for discussion of how clinical supervision and journaling were contributing to the methodological underpinnings of the research process.

3.3.1 Unforeseen researcher burdens

There were three areas of emotional burden that had not been considered during study design. These areas became apparent once data collection commenced. The emotional burden of being immersed in participant grief through transcription and thesis writing was one aspect not considered. Another was the emotional burden of an interview in which the participant described the extremely traumatic birth and death of their baby part way through the data collection phase. The nature of having sole interaction with grieving participants was a new experience and led to difficulties of not knowing how the participants were after the interview and into the future. This was the third burden. Despite the unexpected nature of these experiences, the general support strategies already in place met some of my psychological needs,

however adjustments were required to ensure ongoing health and wellbeing. This section presents the issues, alongside strategies and reflection on events.

3.3.1.1 Transcription burden and being immersed in the thesis

The emotional burden of being immersed in difficult, emotional narratives had not been anticipated beyond the actual interview and data transcription. This was particularly evident with some interviews that were more emotive than others in which participants shared particularly distressing circumstances and feelings. Transcription of interviews took from 8 hours to 16 hours. The most emotionally distressing interview was also the longest interview and took 16 hours to transcribe. Being immersed in difficult narrative provoked personal sadness, inability to concentrate on other work for a short time-period and intrusion of sadness into thoughts outside work. These experiences prompted exploration of the literature regarding the burden of transcription. Other researchers have experienced the same phenomenon and have phrased this 'transcriptionist burden' (Benoliel, 1975; Wiegand et al, 2008). This experience of sadness has been noted by researchers transcribing and in those individuals only undertaking transcription.

Once transcription burden became apparent, the following strategies were developed to limit the emotional sequelae of the experience. A purposeful break between interview and transcription was planned. In most cases, transcription was not commenced until two or three days after the interview in order to allow the emotional burden from the interview to dissipate before adding the burden of transcription. I found, too, that taking regular breaks from the transcription mitigated the challenging nature of the experience. This was not a scientific exercise, it was experiential, unpredictable and iterative, but frequent breaks seemed to help, especially after a difficult description of an event. Planning my clinical supervision appointments after or during transcription seemed to help. As each interview and transcription was completed, the coping strategies evolved. During data collection, with these strategies in place, I did not perceive any long-lasting psychological effects from collecting and transcribing the data. In contrast, once I finished transcribing and moved into data analysis for a participant, I felt more able to disconnect the emotional element of the words. This may be because at this point, I was connecting the narrative less with the person and their voice and moving more into a mode of analysis and the research processes. Other researchers have suggested that in

addition to breaks during transcription, those transcribing should also have scheduled time off to recover emotionally and recharge (Wiegard et al, 2008). Unfortunately, this strategy was not possible with full-time work alongside part-time doctoral study. Regardless, I am sure this would have been beneficial, and I intend to build this into any similar post-doctoral work.

3.3.1.2 Traumatic Narrative

When undertaking research with bereaved participants there is an expectation that narratives will be distressing and emotional, and that some of that burden will transfer to the researcher, however briefly. Yet, due to the longevity of my experience as a neonatal nurse and bereavement support nurse, I did not expect to feel such an emotional reaction to one extremely traumatic narrative. This was my fifth interview and I had become confident that I could manage my emotions in relation to the conversation. However, the nature of the narrative and the need to remain professional in a long interview meant that I experienced feelings of emotional upset and intruding sadness after the interview concluded. This experience is referred to in the literature as 'vicarious traumatisation' and is similar to compassion fatigue or secondary stress (Baird and Kracen, 2006; Wicks, 2006). I had overestimated the breadth of my experience and felt sure that I had observed and been part of most of the experiences that parents would discuss. Yet, I had not encountered a birth and death experience as traumatic as this participant described. I felt an urgent need to discuss the emotions arising from the interview with my clinical supervisor. The supervisor was available for an urgent appointment on the same day, allowing me to release the emotions of the experience without breach of confidentiality. Despite the clinical supervision, some intruding sadness and emotions remained for a few weeks after the interview. Additionally, transcription of this interview was protracted due to the length of the interview. Many breaks were needed during transcription to deal with the emotive nature of the narrative. Once again, this experience has not had a long-lasting psychological effect, although I think about this interview and participant more than any other in this study.

It is possible to underestimate the impact that a participant narrative can have on the researcher. I made presumptions that moving from a nurse-parent therapeutic relationship to a nurse researcher-participant research relationship would equate to less of a caring relationship. On reflection, a researcher-participant relationship

should still contain the core conditions of therapeutic relationships of congruence, respect, empathy and unconditional positive regard (Rogers and Freiberg, 1994). The feelings of empathy and resulting sadness from a difficult narrative are inevitable.

3.3.1.3 Brevity of researcher-participant relationship

I expected the relationship with participants to differ from previous therapeutic relationships that I had experienced with bereaved parents. However, I had not anticipated being left with an unfulfilled need after the interview to know whether participants were managing emotionally immediately after the interview and in the longer term. My previous experiences with bereaved families lasted through multiple interactions and normally encompassed supportive strategies moving from a position of significant distress to an improved position of function and well-being, or referral to another professional for more focused support. I was always able to follow that journey and maintain contact with families until they were experiencing improved well-being. I found it difficult to have engaged with research participants empathically and with compassion, only then to have to disengage immediately without knowing their long-term outcome. This is something that has been explored in some depth through clinical supervision. It remains an unfulfilled concern, but clinical supervision has assisted my ability to accept this fact.

Reflexivity about these unforeseen burdens was essential (Sivell et al, 2015). If left unattended, then there was the potential risk for intruding sadness to perpetuate. Consequently, this could have jeopardised later participants' experiences. Recognition of the potential impact of a lack of reflexivity is crucial to ensuring preservation of the research methodology alongside good ethical practice (Kendall and Halliday, 2014). The use of journaling promoted a reflective approach to these issues as they arose. On completion of the thesis, there had been no long-term sequelae to my health and well-being arising from undertaking this research.

3.3.2 Lone working

The study involved me, as a lone worker, visiting parents in their homes in most instances. As the research interviews were anywhere in the north-west of England, the geographical safety of homes according to area was not always known. A risk-based approach was taken to lone-working and the following strategies were utilised

(Long, 2007). The timing of visits were planned carefully, no visits occurring after 7pm. An action plan was in place for each visit: I always had a mobile phone available, I took note of the exits in the house and how I would exit urgently if needed, an expected completion time was communicated to a third party, and a phone call was made to the third party at the end of the interview. A strategy was in place for a potential situation in which contact with a named person was not made after the interview. The lone worker policy was followed (University of Salford, 2010). Being a lone-working researcher adds further vulnerability to the role as it is difficult to predict the interview environment or the emotions of the participants. In addition, the experience of being a lone-working researcher, added an element of stress and uncertainty to each interview, but as rapport was made with participants the stress of entering an unknown environment settled. There were no episodes where I felt at undue risk as a lone worker, and no situations arose in participants' homes in which I felt at risk. I visited a range of environments and none felt threatening. However, it is appropriate to be cautious, follow organisational procedures for lone working, and have strategies in place to minimise potential risks.

3.4 Ethical approval

Formal approval was obtained for the study from a local NHS REC (dated 08/08/14, reference no: 14/NW/1007), two research and development (R&D) departments in local NHS trusts and from the University of Salford (dated 27/06/13, reference no: HSCR13/21). The research ethics committee approval letters for this study are presented in Appendix II. The R&D departments required me to undertake National Institute of Health Research (NIHR) Good Clinical Practice certification. Significant development work was undertaken, including PPI, to ensure that all ethical issues were addressed prior to application for ethical approval (INVOLVE, 2015). The PPI in this study is discussed in more detail in Chapter 5.

The NHS REC offered positive feedback about the validity of the study and the need for investigation into these issues, as little research was currently available. Additionally, the committee noted that the research was well designed and of potential benefit to future parents in similar circumstances. The general ethical considerations for this study included ethical recruitment, informed consent, confidentiality and data protection, storage and handling.

3.4.1 Ethical recruitment procedures

Potential and actual participants were treated with respect, dignity and sensitivity (NMC, 2018). The recruitment procedures required an ethical risk-based approach. All potential participants were contacted initially through the bereavement staff at the two recruitment centres. Close attention was given to the sensitivity of the study materials sent out to potential participants through PPI consultation, the details of this and how potential participants were recruited are discussed in Chapter 5, Section 5.2. and 5.3.1.

3.4.2. Informed consent

Research governance requires that informed consent must be sought from all research participants prior to data collection and the form itself must adhere to the Health Research Authority (HRA) guidance. The HRA protects and promotes the interests and safety of the public participating in research. Although there is now updated guidance from the HRA, during the data collection period of this doctoral study, the 2014 HRA guidance was in place and will be referred to. The consent form was developed from the exemplars of good practice on the HRA online research support packages (HRA, 2014a&b). Two specific additions were made to the consent form including consent for audio recording of the interview and agreement to be involved in participant feedback at a later date. The NHS REC approved the consent form after the following modifications were made: addition of boxes next to each point for participant initials and a standard paragraph provided by the NHS REC stating that medical notes may be accessed for the research study, even though this was not relevant to this specific study. The final version of the consent form is presented in Appendix III.

Informed consent is implied when prospective participants contact the researcher to participate. There is suggestion that informed consent is impossible in qualitative research because neither the researcher nor the participant know how the data will emerge through the process of interviewing (Streubert and Carpenter, 2011). However, clear and explicit information about the nature of the research will guide prospective participants to an informed decision. The procedures to obtain informed consent are discussed in Chapter 5, Section 5.2.4.

Two copies of informed consent were taken, one for the participant and one for researcher, in accordance with research governance frameworks (HRA, 2014). Permission to audio-record the interviews was given by all participants but one, in that particular case, detailed field notes were taken. Audio recording allowed for active listening, appropriate prompts to be made and no need for note taking, which can be off-putting for some participants (Ritchie, Lewis, McNaughton-Nicholls and Ormston, 2014; King and Horrocks, 2010). The rights of the individual were considered with participants having the right to be informed, to withdraw from the study at any time, without prejudice and the right not to be harmed (Williamson, 2007). Participants were fully informed of their rights in the opening conversation.

3.4.3 Confidentiality and anonymity

Confidentiality is a term that needs clear explanation with potential and actual participants as the term indicates that no information would be shared outside the participant-researcher relationship (Williamson, 2007; Smith et al, 2009).

Confidentiality refers to the handling of participants' contact information and any identifiable materials. Access to participants' identification or details were available only to the researcher and were kept according to NHS REC data handling specifications. Further, the researcher's adherence to confidentiality in accordance with the NMC Code was also necessary (NMC, 2018).

Anonymity was discussed with all participants alongside the context of confidentiality prior to giving informed consent. All participants were informed that this study was part of a doctoral programme and that supervisors might see transcripts of the raw data but anyone else would see only edited work that would be anonymised with codes. In fact, supervisors saw only anonymised data in the form of transcripts. Further thought had to be given to the potential recognisability of a small study sample and the hospital trusts in which their baby was cared for. Anonymity provides appropriate safeguards for participants, even with a small sample size. Referring to tertiary NICU narrows down the possible sites, but as there are two tertiary NICU in the north west of England and so the location remains anonymous. All participants agreed to the use of direct quotations in any professional outputs including this thesis but with referral to their identity as a number.

3.4.4 Data protection, handling and storage

This study complied with the data protection legislation of the time, and NHS governance procedures regarding data handling and storage were followed. All identifiable data such as personal contact information about participants, consent forms and field notes were stored securely in a locked filing cabinet, in a locked office on university property with restricted access, according to the requirements of varied agencies (NMC, 2018; DH, 2005; Data Protection Act 1998). When interviews were conducted and personal contact information and consent forms were, of necessity, with the researcher, these were returned to the secure facility without delay.

Audio and electronic data were also stored under the same conditions in a locked office. All electronic data including sound files and MS Word documents were kept in a dedicated area of a secure, password protected university server accessible only to the researcher. Audio data was immediately transferred to the secure computer server and then wiped from the audio recorder after each interview. A back-up of all data was kept on a removable hard drive but stored in the same way as other study materials. There were no breaches in data protection, storage or handling.

3.5 Summary

This chapter has presented the general and specific ethical concerns associated with this sensitive research study. In-depth discussion of the potential risks to participants and strategies to address any distress arising from the research has been presented. Researcher well-being is often not a significant concern in research studies, however the early planning for this risk was crucial in devising strategies that maintained my emotional and psychological health and wellbeing. The breadth of learning that I undertook in relation to my own needs as a researcher was substantial, and I realised several issues and improvements that would enhance future research in the same field.

Reflection point 3.3: lessons learnt from the burden of bereavement research

I would suggest for future research in the field that it would be better to research in a group of two or more researchers, where the burden of the narratives could be discussed and debriefed. In a group of researchers, transcription could be resourced and completed externally, or audio recordings swapped to transcribe one another's interviews. Breaks of a week or more should be planned between interview and transcription. Finally, clinical supervision could include group discussion as well as one-to-one supervision, benefitting all researchers by sharing of similar issues. Despite the changes suggested for future research in this context, I remained passionate about this research while wanting it to be a safe experience for both participants and researchers

Chapter 4 – Study design: rationale for methodology and methods

4.1 Introduction

Study design and methodological considerations are presented in this chapter, with application of the methods detailed in Chapter 5. The rationale for the study design is offered along with a critique of the methodological approaches that could have been adopted to explore parents' experiences and perceptions. Ethical approval is not addressed in this chapter as this has been fully covered in Chapter 3. The reasons for choosing interpretive phenomenological analysis as the methodological approach to explore the experiences of bereaved parents are offered. First, the study aim, objectives, and setting are outlined.

4.2 Aim and objectives

The overarching study aim was to explore parents' experiences and perceptions of support needs during and following the death of their baby. The specific objectives were to:

1. Describe parents' experiences during and following the death of their baby;
2. Identify the impact of their baby's death on parents' lives;
3. Ascertain the support mechanisms utilised by parents to cope with the death of their baby;
4. Identify the support mechanisms that health professionals/services could implement or develop to assist parents to cope better with the death of their baby.

Describing and understanding parents' experiences and the impact on their lives of their baby's death, together with identifying their needs for support was an essential preliminary to further (postdoctoral) work to implement and evaluate the required support.

4.3 Study setting

In the UK, sick neonates are cared for in neonatal units, which are designated into three categories, relating to the level of care required, as discussed in Chapter 1, Section 1.2. In the Northwest Neonatal Operational Delivery Network (NWNODN), there are 22 neonatal units (7 NICU, 13 LNU, 1 SCU and 1 NSU [neonatal surgical unit]). Two sampling sources were employed in order to capture a range of experiences in relation to services offered. One NICU resourced a bereavement team, whilst the other NICU did not offer any bereavement after-care at the beginning of recruitment, however a part-time bereavement support post was introduced early in the study. The local differences in provision of end of life and bereavement care had the potential to add to the evidence base regarding the range of experiences encountered by parents in the UK. It is possible that some babies might have had palliative care on the NICU but went on to die in a hospice or home setting. These babies were included when recruiting participants. It was also possible that some babies might have been cared for previously outside the NWNODN but died in the North West. These babies were also included in the study sample. Data were collected according to participant preference, either in their own home or in a different venue of their choice, for example the university.

4.4 Study design and methodological considerations

An interpretive phenomenological analysis (IPA) design was adopted to enable an in-depth, participant-centred exploration of parents' experiences during and after the death of a baby. This section presents the rationale for the study design, and a critique of the epistemological and ontological assumptions associated with qualitative research, phenomenology, and more specifically IPA.

Qualitative research is a broad term that encompasses a range of research methodologies that enable complex situations to be explored through a specific 'lens' in a range of contexts. Broadly, qualitative research seeks to gain a deep and holistic perspective of the phenomenon being studied, where the context is not only the participants and setting but it is also the researcher's role within that context (Gray, 2014). Whilst there is no definitive way to classify qualitative research designs, they can be divided into four broad groups, grounded theory, ethnography, descriptive qualitative methods and phenomenology, each with different ontological and

epistemological underpinnings. These qualitative designs were considered suitable to explore parents' experiences during and after the death.

Qualitative designs, such as grounded theory (GT), use an inductive approach in order to develop and establish theory (Gray, 2014; Starks and Trinidad, 2007). GT is a design founded in pragmatism and it is particularly relevant when little is known about a certain phenomenon or where new perspectives are needed. In a GT study, theory emerges from the empirical data and although grounded in participants' perspectives there is no claim to reflect these perspectives in entirety (Wimpenny and Gass, 2000). However, new theory is not always the result of a GT study: clarity over conceptual understanding or a conceptual framework may be the result (Timonen, Foley, Conlon, 2018). GT was considered because it is useful to facilitate prediction and rationalisation of behaviour, providing a perspective on that behaviour (Glaser and Strauss, 1967). A possible research question related to the thesis focus using a GT design was, 'How do parents experience grief and support after the death of their baby?' However, an explanatory theory, conceptual understanding or examination of processes was not the aim of the research and I had a deep-seated desire to view the phenomenon through the parental lens. In addition, theories about grief in the context of bereavement exist and have been extensively researched, as discussed in detail in Chapter 1. Therefore, grounded theory was excluded as a suitable method for this study.

Ethnographical designs are concerned with learning about people, behaviours and actions, this is normally achieved through an immersive approach such as observation, interviewing and sometimes engaging in activities (Atkinson and Hammersley, 2007; Jones and Smith, 2017). Atkinson and Hammersley (2007) suggest that ethnography does not have a well-defined meaning because of its association with a range of disciplines, contexts and reinterpretations. Whilst ethnography is founded in more than observation, observing participants is still a core element of the method by which a study is undertaken, and being in the natural setting is fundamental to the design. A potential research question was prepared: 'How do parents experience end of life care and grieve during and following the death of their baby?' The elements of observation and natural setting were problematic for this study as it would have been possible to observe the end of life experience but ethically inappropriate to intrude on such personal and private

moments for research purposes. In addition, to observe grief would have been difficult due to the protracted nature of the experience, which again would be invasive and intrusive. Therefore, ethnography as a design was excluded.

Ethnographical approaches also include socio-linguistic methods such as discourse and conversational analysis, which are particularly relevant to explore the meaning of language, dialogue and the depth and value of interactions (Potter and Wetherill, 1987; Schegloff, 2007). For example, in the context of this study, socio-linguistic methods could be used to explore the way in which health professionals discuss end of life care with parents; but this would not capture participant's thoughts and feelings of the phenomenon. Further, there would have been a need to observe and audio or video record these conversations, prompting difficult ethical concerns in relation to obtaining informed consent at such a fraught time in parents' lives. Therefore, this design was excluded as not meeting the proposed aim of the study and too intrusive.

Descriptive qualitative methods without a philosophical underpinning were considered alongside a phenomenological approach. Descriptive qualitative methods would have been suitable because the broad aim was to explore parents' experiences and perceptions of support. In addition, the data collection and analysis methods used in descriptive qualitative methods are often based on general principles of qualitative research and can be applied across a range of study settings (Daly, Willis, Small, Green, Welch, Kealy, Hughes, 2007). Descriptive qualitative methods have been criticised for being superficial and lacking in rigour because of the absence of theory. However, descriptive methods offer flexibility in the way the data is collected, and the analytical strategies adopted, allowing scope for innovation (Kahlke, 2014). This approach to qualitative research is increasingly common, particularly in healthcare settings, where patient experiences are being sought, despite few guidelines to direct the process (Caelli, Ray and Mill, 2003; Sandelowski, 2000). While a purist approach with a defined underpinning methodology does not guarantee a robust study design, critics suggest a greater critique of descriptive methods is required to define what is considered 'good' descriptive qualitative research (Caelli et al, 2003).

In contrast, phenomenology had the potential to facilitate obtaining rich data through interviews that are less structured, with meaning that is co-constructed between the

participant and the researcher. Further, the philosophical underpinnings of phenomenology are based on understanding what the experience is like or means to the participant, with the researcher's role to represent, describe and interpret participant accounts (Tuohy, Cooney, Dowling, Murphy, Sixsmith, 2013). The differences between the main traditions of phenomenology and rationale for choosing IPA are presented in the next section.

4.4.1. Phenomenology, foundations and application to research

A phenomenological lens using IPA was adopted to underpin the study because the aim was to understand the lived experience and the unique meaning of the death of a baby for parents in an unpredictable and difficult setting. While the discipline of phenomenology is well established, IPA is a relatively new method for undertaking interpretative phenomenological research. The processes associated with IPA were developed in the 1990s by Smith (1994), however, it is grounded in hermeneutics and Heideggerian phenomenology, which in turn originates from Husserl's phenomenological philosophical foundation. The term 'phenomenon' originates from the Greek language and is broadly translated as 'showing itself' or 'to bring into the light' (Heidegger, 2008, p.52; Pringle, Hendry, McLafferty, 2011). Phenomenology was simply defined by Husserl (1906), the founder of phenomenology, as the "experiences of thinking and knowing".

Phenomenology was first established as a philosophy by Husserl who, along with his students, debated his thinking of consciousness and forms of being or objects (Moran, 2000). Ambitious research projects were developed and over the years he and his students pushed the boundaries of his initial thinking and postulated that 'bracketing' or 'phenomenological reduction' (a suspension of prior knowing) of knowledge and beliefs was fundamental to the philosophy and that the phenomenon should be viewed simply as it is experienced (Husserl, 1906). Bracketing has been described as a shedding of prior knowledge (Lopez and Willis, 2004). The purpose of bracketing is to ensure that researcher 'remains true' to the phenomenon without the influence of their own views, ensuring objectivity within the study (Dowling, 2004; Fleming, Gaidys and Robb, 2003). Bracketing was contentious and not shared by some of Husserl's peers and students in the phenomenological movement such as Heidegger and Scheler (Moran, 2000). Bracketing continues to be subject of debate

and criticism, particularly whether it is realistic or even possible for a researcher to set aside their knowledge and expertise (Finlay, 2008; Wimpenny and Gass, 2000).

Husserl further developed his philosophical stance establishing phenomenology as a method of undertaking research, now widely understood and labelled 'descriptive phenomenology'. Phenomenology in the Husserl tradition seeks the construction of meaning from exploring the individuals' experiences and the development of a narrative of their experiences. It is through the process of focusing on particular experiences that meaning is attached to those experiences, in collaboration with the participants and so, a discrete phenomenon becomes understood (Husserl, 1906). Husserl's approach to phenomenological research sought to describe the phenomenon accurately, and not to interpret participants' narratives (Husserl, 1906). However, it has been argued that all phenomenological investigations and qualitative research in general, involves an interpretive element in order to make sense and contextualise findings (van Manen, 1997). In descriptive phenomenology (DP), bracketing in the Husserlian tradition is generally accepted as an essential component of the process.

Heidegger furthered the philosophy by exploring consciousness from the perspective of existence and 'dasein' (being in the world) and his methodological approach of undertaking research projects through the possibilities of situations. His phenomenological philosophical stance moved from Husserl's descriptive position to the interpretive or 'hermeneutic' discipline of phenomenology (Pringle et al, 2011). Shared meaning underpins this tradition of phenomenology, and Heidegger believed that each person is a self-interpretative being (McConnell-Henry, Chapman and Francis, 2011). Heidegger re-affirmed Husserl's belief that there is no single universal expression or behaviour (eidos), and that experiences and perspectives are not only temporal, but a range of interpretations are possible, each of which may be valid (Flood, 2010). Therefore, participants' interpretations are fundamental to the process of meaning-making from Heidegger's position of phenomenology. It is from this philosophical stance that interpretive phenomenology is derived (Smith et al, 2009).

In Heidegger's tradition of interpretive phenomenology (IP), bracketing is not advocated (Lopez and Willis, 2004). From the Heideggerian stance the researcher does not bracket their knowledge or expertise but makes their knowledge explicit and

accounts for their perspectives during data collection and analysis. Furthermore, a study can be strengthened if the researcher is situated in the research, where mutual language can be understood and the researcher can bring relevant context to the investigation (Smith et al, 2009). Prior knowledge and experience should be acknowledged, valued and embraced to facilitate the investigation, processes and interpretation, and these are valid elements of the research (McConnell-Henry et al, 2011). However, this validation of prior knowledge does not mean that assumptions can be made about the phenomenon. An openness and desire to listen and value participants' experiences are essential to the credibility of the study, but more importantly, to ensure authenticity in relation to the philosophical foundations of the research method (Lopez and Willis, 2004).

Hermeneutics originates from a Greek verb meaning 'to interpret' (Eatough and Smith, 2008). It is the experience of thinking through understanding and interpretation, and Heidegger was one of the theorists contributing to its understanding along with Gadamer, Ricoeur and Habermas (Tomkin and Eatough, 2018). The term hermeneutic has been further described as the ability to reveal what is hidden about the human experience and relationships (Lopez and Willis, 2004; Spiegelberg, 1976). It is from this hermeneutic phenomenological philosophy that interpretative phenomenology developed.

The ontological origins of phenomenology in the broad sense aim to represent the true 'nature of being' rather than any subjective imaginings that do not represent the reality. The epistemology of phenomenology as a research methodology is based in revealing meaning rather than proving an argument or developing new theory (Flood, 2010). Meaning is constructed through engagement with the world that is being experienced and interpreted, and the robustness of the data analysis to understand the phenomenon; assumptions are not part of foundational thinking in phenomenology. The researcher aims to analyse the experience of the participant, perceive how the phenomenon is given meaning, and interpret how it is embodied in the real world (Flood, 2010). In phenomenology, interpretation does not only sit in the domain of the researcher; the participant's own interpretation is a key element of the research approach (Smith et al, 2009). Figure 4.1 presents the aims of descriptive and interpretative phenomenology and the key characteristics and differences between the approaches.

Descriptive Phenomenology Husserl	Interpretative Phenomenology Heidegger
Aims and Characteristics	
Describe phenomenon's characteristics Describe experiences as they appear to the consciousness Consciousness is the medium between people and the world Time and space are not considered but set aside Focus on experience alone, not context Bracketing (reduction) used to set aside natural, everyday assumptions Describe phenomenon in its purest form Can only 'bear witness' to experiences	Describe individual experiences Describe, understand and interpret 'being' in the world Hermeneutic circle is a vital component to viewing the phenomenon through the participants' lens Time and space are important concepts Focus on context, not just experience No bracketing Determine meaning Life world and existential themes Epistemology – revealing meaning Interpret belief – accept participants' stories albeit in a questioning way Idiographic nature

Figure 4.1 Comparison of Descriptive and Interpretative Phenomenology

There are several criticisms of phenomenology as a research methodology (Gray, 2014; Wimpenny and Gass, 2000). The in-depth accounts that are generated, result in detailed description of the phenomenon and small sample sizes. This has led to criticism that findings cannot be generalised to other settings (Sandelowski, 1997). Generalisability is not normally an aim of qualitative research; rather a fresh, unique and rich understanding of experience is the goal (Sandelowski, 1997). In addition, deep and richer accounts of participants' experiences are a central tenant across phenomenological approaches. Phenomenology is not concerned with generalisations to larger samples but rather with description and analysis in the context of the study setting, true to participants' world views (Gray, 2014). In addition, the quantitative test of generalisability is not appropriate to qualitative studies. Further criticisms of phenomenology relate to the unstructured nature of the method, where misunderstandings of the methodological approaches can lead to a lack of

clarity and slurring of the processes and findings (Winterpenny and Gass, 2000; Pringle et al, 2011). However, the unstructured approach to data collection aims to facilitate co-construction of data, themes and findings without assumptions, which, in contrast, is a strength of the method.

The epistemological foundations of DP have been criticised because searching for order in experience and between differing experiences is subjective and lacks rigour (Holloway, 2005). Those critiquing the methodology have suggested that rather than searching for order and priorities, researchers can offer only multiple perspectives and context. Methodological criticisms centre on a loss of the philosophical foundations when phenomenology is translated into practical research methods (Crotty, 1996). Further criticism questions whether there can be description without interpretation and that all qualitative research findings require interpretation to create a meaningful narrative (Holloway, 2005; van Manen, 1997). The purposeful use of small, homogenous samples has led to suggestions that relevance to other groups is significantly limited (Pringle et al, 2011). This tension can be surmounted if limitations are clearly stated and acknowledged, allowing a rich, transparent account of the research (Smith et al, 2009; Pringle et al, 2011).

Building on the work of Husserl and Heidegger, different approaches and applications of phenomenology to research have developed, including work by Gadamer who furthered the thinking on philosophical hermeneutics and whose work focused on hermeneutics being a living, shared pursuit. Arendt, one of the few female phenomenologists, pioneered phenomenology in the public sphere, and was interested in how things appear. Levinas developed the nature of meaning and ethical relations through phenomenology, with concern for others being central to his work. Merleau-Ponty furthered Husserl's stance on 'being in the world' and developed phenomenology of perception (Moran, 2000). More recently, phenomenologists such as van Manen (1997) have developed and progressed research approaches in hermeneutic phenomenology and pedagogy. Smith et al, (2009) offer a practical approach for using IPA originally based in psychology but with application in wide contexts, and Crotty (1996) advanced the application of phenomenology in a nursing context.

4.4.2. Rationale for adopting an interpretive methodological approach

Interpretive phenomenological analysis (IPA) was chosen as the most suitable qualitative research method to meet the study aims because, in common with other phenomenological approaches, it is relevant for exploring and understanding participants' lived experiences (Tuohy et al, 2013). Smith et al (2009) have refined the method for undertaking IPA, and their text 'Interpretative Phenomenological Analysis: Theory, Method and Research' was used to guide this research and is used to support the methodological decision-making rationalised in this thesis. Although descriptive phenomenology could have met the broad research aim, it would not have met all the research objectives. A pure description potentially would have limited the ability to interpret the impact of the death of a baby on parents' lives and the support mechanisms that could assist parents cope with the death of their baby.

Central to IPA is revealing the unique meaning and significance of the phenomenon by those experiencing it, when it can then be described and interpreted (Smith et al, 2009). IPA was an appropriate choice to meet the study aims for several reasons. It is an inductive approach, which facilitates gaining a deeper understanding of experiences. As an experienced bereavement nurse, it would be difficult to 'bracket' prior knowledge and experiences. Prior knowledge of neonatal and bereavement care has been accounted for and acknowledged throughout this thesis, and this will be advantageous to facilitate in-depth interviewing (Wimpenny and Gass, 2000). Finally, the idiographic nature of IPA is appropriate for bereaved participants because of the individualised and unique experience of grief. IPA offers the ability to be idiographic and be concerned with the particular individual participant's narrative, but it is not isolated to single case study research. Later in the IPA process, after an idiographic approach has been taken there is opportunity to apply a nomothemic approach where as well as being able to take a more nomothemic approach where themes across participants' narratives can be linked.

Researchers interested in the psychology of the human predicament and whose epistemological perspectives placed participants central to nature and direction of the data collected were early adopters of IPA (Smith et al, 2009). However, IPA has become more widely used, not just by health professionals, but researchers wanting to explore the psychological experience of a phenomenon (Smith, 2011). I anticipated that adopting the philosophical perspective of IPA would assist parents to

direct the topics discussed and therefore facilitate them to share their personal viewpoint. In interpretative phenomenology, the researcher's role is to uncover meaning embedded in participants' accounts and to acknowledge their role, knowledge and experience in the construction of meaning from the participants' world view (Pringle et al, 2011). Central to IPA is the 'hermeneutic circle', which can be thought of as the dynamic relationship between the part and the whole. As the researcher investigates the phenomenon of interest, they move iteratively between smaller units of meaning to larger units of meaning, particularly in data analysis (Smith et al, 2009). This iterative process provides opportunity to go beyond surface level description to provide insightful interpretative accounts and sense making of participants' lived experiences (Larkin, Watts and Clifton, 2006). Figure 4.3 presents examples of the part and the whole in the context of the hermeneutic circle.

The part	The whole
The single word	The sentence in which the word is placed
The single extract	The complete narrative
The particular narrative	The collection of narratives
The interview	The research project
The single experience	The complete life

Figure 4.2 Application of the hermeneutic circle (Adapted from Smith et al, 2009)

Bracketing and epoché, meaning a suspension of judgement, are unrealistic boundaries in this research due to my previous experience in this field. Bracketing is not a requirement in IPA, however, rather than setting aside knowledge that influences understanding and fore-structure, which is described as what is known or understood before interpretation and what stems from prior experience, that knowledge should be recognised and acknowledged (Finlay, 2008; Smith et al, 2009). The idea of 'bridling' preconceptions is suggested by Dahlberg, Dahlberg and Nyström (2006) and reaffirmed by Eatough and Smith (2008) for its use in IPA. Bridling was used as a metaphor to describe three areas: restraining preconceptions, not making definite what is indefinite, and directing focus forward into an open attitude that allows the phenomenon to present itself (Dahlberg et al, 2006). The intention in this doctoral study was to utilise the concept of bridling as appropriate to limit assumptions and preconceptions, and to facilitate an open

approach to data collection and analysis whilst being able to utilise knowledge and experience appropriately for interpretation.

In summary, phenomenological research is based on the two theoretical approaches of descriptive phenomenology (DP), initially developed by Husserl, and interpretative phenomenology (IP), initially developed by Heidegger (Husserl, 1906; Heidegger, 2008). Both DP and IP focus on the lived experience. DP seeks to bring out the core components of the lived experiences distinctive to a group of people (Flood, 2010). In contrast, IP focuses away from the person, people or phenomenon and concentrates on exploring the lived experience itself, also known as the 'dasein' (Flood, 2010). IP intends to move beyond description of essence to explore what people experience rather than what they might consciously know. Therefore, the ontological focus of IP is on how interpretation is intrinsic to human existence (Flood, 2010; Smith et al, 2009). IP starts with fore-structure and aims to reach the essence of a phenomenon through a series of reductions, known as eidetic reduction and this is described as a technique to find the essence (Smith et al, 2009). Each reduction aims to lead the researcher away from distractions and misapprehensions to the true essence of the issue being explored (Smith et al, 2009).

IPA is a research design that has evolved from Heidegger's hermeneutic stance on phenomenology and a practical process for undertaking research using this method has been developed by Smith et al (2009). IPA was the research methodology chosen for this doctoral study and the method is now presented.

4.5 Methods

4.5.1 Sample selection strategy

An effective strategy for recruiting prospective participants is crucial if study aims are to be achieved. Purposive and theoretical sampling are the most common research sampling strategies in qualitative research, however, the terms are often used interchangeably, though erroneously (Coyne, 1997; Ritchie et al, 2014). The differences between sampling strategies relate to whether sampling criteria are determined prior to data collection or adapted in response to preliminary data analysis. In purposive sampling, selection criteria are predetermined, albeit in theoretical sampling there is subsequent modification of the selection criteria as the

study evolves, enabling participant recruitment to be refined. Both purposeful and theoretical sampling aim to select participants who have had experience with or an interest in the phenomenon. Further approaches can be added to purposive sampling such as snowballing, where one informant identifies or introduces another. This is useful if the participants are difficult to find or contact (Streubert and Carpenter, 2011).

Robinson (2014) suggests there are four components to sampling in qualitative methods: a sample world, sample size, sample strategy and sourcing the sample. In IPA, it has been suggested that the study sample should be homogenous, although the degree of homogeneity will vary according to the phenomenon being investigated (Smith et al, 2009). The purpose of having a homogenous sample is for both practical and interpretative reasons. Although recruitment of a heterogeneous sample is often more desirable in applied research, homogeneity can facilitate a more detailed analysis, and participants from a homogenous sample will still have different experiences. However, homogeneity can be a weakness of the study if the participant group is highly specific or unique and may limit the findings in terms of broad context (Pringle, Drummond, McLafferty and Hendry, 2009). A purposeful sampling strategy was adopted for this study, selecting participants using predetermined criteria. In keeping with this, inclusion and exclusion criteria were established in advance of recruitment (Figure 4.3). The inclusion criteria were broad and included parents over the age of 16, where their baby died in an NICU, at home, or in a hospice after discharge from NICU regardless of the cause of death. This study was designed with theoretical foundations relating to adult grief patterns, so only adult parents were included.

Of those parents who met the inclusion criteria, it was appropriate to exclude parents of babies that were involved in an ongoing coroner's inquest. Most such inquests are resolved by six months; however, it is possible for this process to be lengthy with an undecided outcome. Neonatal deaths subject to a coroner's inquest are a complex and particularly difficult process for parents, and it would have been inappropriate to complicate parents' journeys further by inviting them to participate in research until the inquest was complete. In addition, those parents who were unable to speak the English language were excluded, as no funding was available for interpreting

services. The lack of funding for interpretation is a limitation of this study and is discussed in more detail in Chapter 7, section 7.2.

Inclusion Criteria	Exclusion Criteria
Parents whose baby died on a neonatal unit in the north west of England OR Parents whose baby had most of their care on a neonatal unit in the north west of England but died at home or in a hospice Parents over 16 years of age	Parents who do not speak fluent English Parents whose baby's death was subject to an ongoing Coroner's inquest

Figure 4.3 Inclusion and exclusion criteria

Sample sizes for qualitative methods are typically small, as the richness of the data obtained and analysis processes are detailed (Gray, 2014; Sandelowski, 1997). However, a sufficient number of participants is needed to capture a range of experiences. Sampling in qualitative research is a matter of judgement and experience (Sandelowski, 1997). For a novice research student, supervisor expertise in sampling is crucial. Envisaging sample sizes at study design stage is problematic and does not enable flexibility to adjust the sample in response to the iterative nature of qualitative research, where data collection and analysis may be undertaken simultaneously. Decisions regarding when to stop recruiting participants are influenced by the depth of data collected, emergent themes and pragmatic matters of timing and recruitment. Judgement regarding whether the research aims have been met within current sample size can be made only as the study progresses. In IP, the aim is quality of data, not quantity, leading to a detailed account of individual experience. Smith et al (2009) offer suggestions for sample size related to student projects and doctoral studies from three to twelve participants. However, they advocate flexibility and a move away from prescribing exact numbers. Larger sample sizes do not equate to better quality IPA study. In contrast, larger sample sizes may encumber high quality IPA.

4.5.2 Data collection methods

A wide range of data collection methods are used in qualitative research (Speziale and Carpenter, 2007). In IPA, data are normally collected by semi-structured or

unstructured interview because the ability to have meaningful interaction with the participant enables the elicitation of the lived experience (Eatough and Smith, 2008). However, other data collection methods can be used in IPA such as diaries, personal accounts and focus groups. Interviews are particularly suited to IPA and this doctoral study as they can facilitate co-construction of meaning between the participant and the researcher, and interpretation is a blending or fusion of those two perspectives (Holstein and Gubrium, 2003; Koch, 1996; Lopez and Willis, 2004; Walker, 2011). In this study, data were collected using unstructured interviews.

Interviewing is a well-established method of data collection and creates the potential to collect rich data (Robson and McCarton, 2015). Interviewing has been described as a conversation with a purpose (Burgess, 1994). However, the conversation in the interview setting is generated artificially, and while a conversation suggests a two-way dialogue, the aim is to prompt the participant to talk. Interviewing should allow participants to tell their stories, to speak freely, to reflect and generate new thinking, and to be granted the time to do this at some length (Smith et al, 2009).

An active interview is defined further as a conversation with a guiding purpose or plan that is organised though relatively flexible. The term 'active' suggests that both researcher and participant have an awareness of the purpose and of their roles in the interview process (Holstein and Gubrium, 1995). The interviewer should avoid dominating the encounter or steering questions in a way that reflects the researcher's viewpoint, as the participant is the central focus of the interview. Nevertheless, the researcher needs to ensure that the research aim is addressed. The skills of the interviewer are a key component of successful active interviewing, with the researcher knowledgeable in cultural and contextual background that encourages participants' responses through mutual language and a shared interest in the subject (Holstein and Gubrium, 1995). Potential for power imbalance in the researcher-participant relationship should be considered and strategies implemented to ensure that this does not affect the interview dynamic (King and Horrocks, 2010).

Time must be allowed to undertake the interview to enable the sharing of participant's experiences. This is particularly important in unstructured interviews due to the open nature of the narrative that is facilitated as the time frames for

unstructured interviewing are more unpredictable (Kings and Horrocks, 2010; Smith et al, 2009). The following parameters for an active process of interviewing are suggested by Floyd, Fowler and Mangione (1990).

1. Read the question as worded;
2. Explore incomplete answers for clarification and elaboration;
3. Record answers without discretion; a true account of the answer;
4. Interviews should be non-judgemental respecting information shared; positive or negative feedback should not be given.

However, not all elements of the process were directly applicable to the IPA process for this study, for example, reading the question exactly as worded is not in keeping with an unstructured interview. However, stages 2-4 of the active interview were relevant to IPA interviewing as way of enabling participants to share their stories and experiences. Interviewing as a data collection method has both strengths and limitations. The key strengths of interviewing include the ability of researchers to build rapport, the enabling of participants to describe the issues that were important to them, the opportunity for researchers to probe answers further, and the possibility of catharsis for the participants in sharing their story (Doody and Noonan, 2013). The limitations of interviewing include the time commitment for both participant and researcher, and the potential for researcher bias in relation to the development of questions and the way in which the interview is undertaken (Doody and Noonan, 2013). The strengths and limitations of interviewing are presented in Figure 4.5.

Strengths	Weaknesses
<p>Opportunity for participants to ask questions about the study</p> <p>Better for participants with learning difficulties</p> <p>Rapport can be established</p> <p>Can gain insight and context into research question and participant experience</p> <p>Participants describe what is meaningful to them</p> <p>Researcher can make observations of non-verbal communications</p> <p>Questions and answers can be probed fully</p> <p>A more detailed response to questions is possible</p> <p>Researcher and participant can seek clarification</p> <p>Catharsis of telling one's story</p>	<p>Can seem to be intrusive to the participant</p> <p>Time-consuming to conduct, transcribe and travel for the researcher</p> <p>Time-consuming for the participant</p> <p>Sensitive subjects can evoke emotional responses that require experienced and sensitive handling</p> <p>Vulnerable to bias:</p> <ul style="list-style-type: none"> - Participant desire to please researcher; - Saying what think researcher wants to hear; - Need to make a good impression affects participant honesty; - Researcher's non-verbal behaviour can affect participant's responses

Figure 4.4 Strengths and limitations of interviewing (Adapted from Doody and Noonan, 2013)

The key component to data collection within phenomenological methods is eliciting information that meets the study aims while allowing participants to shape the direction of the interview in an active manner (Walker, 2011). Normally in IPA, eliciting narrative to meet the research question is approached indirectly because the language used in research objectives is not natural in everyday dialogue and potentially would be confusing. The style of interview technique in IPA can vary, but a one-to-one, semi-structured interview is appropriate for novice researchers of IPA because an interview schedule can ensure consistency of questions across interviews therefore reducing researcher bias (Reid, Flowers and Larkin (2005). However, whilst semi-structured interviews in IPA can allow the researcher greater opportunity to direct dialogue, they can thwart the co-construction of meaning. In contrast, unstructured interviews are often chosen as an approach in IPA when the interviewer is more experienced. However, due to my extensive experience with bereaved parents in a listening situation, unstructured interviewing was feasible and realistic. It should be acknowledged that the term unstructured is misleading, as all interviews have broad topics that help to shape the conversation (Doody and

Noonan, 2013). This concept of structure within unstructured interviews is debated in IPA, with some phenomenologists advocating that one core questions should be asked at the beginning of the interaction from which the interview unfolds with minimal direction from the researcher (Heffron and Gil-Rodriguez, 2011; Smith et al, 2009; Walker, 2011). For this study, unstructured interviewing was selected as the most appropriate approach for data collection because it allowed for flexibility in the interview and enabled the participant to shape the direction of the interview (King and Horrocks, 2010; Smith et al, 2009).

Unstructured interviews using a brief topic guide can be used to ensure that the interview does not lose focus on the research aims and objectives. A fundamental component of the inductive principles in phenomenological research is an element of unpredictability in in-depth interviewing (Smith et al, 2009). A strength of undertaking unstructured interviews is that the existence or being there (*dasein*) is constructed collaboratively between participant and interviewer (Heidegger, 1962; Holstein and Gubrium, 2003). In addition, greater depth and breadth of data collection is possible because questions are developed from participants' responses, using the topic guide as a steer if required (Fontana and Frey, 2000). There can be diversity between interviews, which is an asset in phenomenological methods, where an idiographic approach and individual narratives are valued and hold their own weight. How each interview evolves in this approach depends on how the participant answers the opening question, which is an intentional and inductive method to enable participants to direct the narrative that develops (Smith et al, 2009). An interview guide was developed to underpin effective unstructured interviewing and is discussed in further detail in Chapter 5, section 5.2.5.

4.5.2.1 Participant units: single and couple interviews

Interviewing is usually undertaken with individual participants on a face-to-face basis, but, although it is less common, two participants may be interviewed together (Eggenberger and Nelms, 2007; Reczek, 2014). There is limited methodological guidance relating to interviewing couples. Once a decision was made to invite both parents to take part in the study, decisions were to be made whether to undertake interviews individually or together. Participant couples were offered the option of individual interviews or being interviewed together.

Taylor and de Vocht (2011) suggested that interviewing couples together helps to establish rapport with the interviewer. In addition, interviewing couples together may improve data collection as parents prompt one another to recall memories of their loss experiences in this instance and negotiate meaning (Seymour, Dix, Eardley, 1995; Taylor and de Vocht, 2011). Furthermore, in a joint interview couples may probe, question, correct and corroborate one another's narrative (Taylor and de Vocht, 2011). There are challenges to be considered when interviewing couples for research. Respondents may experience lack of freedom to express their feelings fully with a partner present, while ensuring the informed consent of each participant and maintaining the confidentiality of the interview can pose problems (Mellor, Slaymaker & Cleland, 2013). One of the significant tasks in interviewing couples is ensuring that consent is informed. There is a risk of co-construction of consent, with the participant who initially enquired as a gatekeeper to consent. The gatekeeper may encourage or coerce their partner's participation (Mellor et al, 2013). The aim is to have the same voluntary participation from each participant, and the processes of informed consent and research governance should ensure that this is achieved (HRA, 2014a). Awareness of the potential concerns about consent when interviewing couple was vital to ensure an ethically irreproachable process.

A challenge of interviewing couples individually rather than together is the issue of maintaining confidentiality. Interviewing a couple together has the potential to eliminate this problem as the narrative is co-constructed and shared. Interviewing separately when both partners are participants risks the researcher disclosing some information from one member of a couple to the other, or shaping the second interview due to an interesting comment from the first partner. Both scenarios have the potential to breach confidentiality (Mellor et al, 2013). Each of the two sets of couples in this study were interviewed together, therefore their narratives were co-constructed.

4.5.3 Data Analysis

Data analysis should be a rigorous and cogent process that gives data meaning (Gray, 2014). The analytic journey does not encompass only formal data analysis, but also includes analytical thinking from design and sampling through to abstraction and reporting of findings (Ritchie et al, 2014). It requires the investigator to use cognitive processes to interpret the data and derive conclusions from the findings

(Streubert and Carpenter, 2011). Qualitative data analysis comprises some of the following processes: reading, intuiting, analysing, interpreting, making cognitive comparisons, discerning patterns, synthesising and reporting findings (Streubert and Carpenter, 2011).

Central to the credibility of qualitative study findings, is the robustness of data analysis. Smith et al (2009) presented six steps to undertake robust data analysis consistent with IPA. Figure 4.6 presents these steps. The application of these six steps are presented in Chapter 5, section 5.3.3.

IPA Data Analysis	
Step One	Reading and re-reading
Step Two	Initial noting
Step Three	Developing emergent themes
Step Four	Searching for connections between emergent themes
Step Five	Moving to the next case
Step Six	Looking for patterns across cases

Figure 4.5 Steps of Interpretative Phenomenological Analysis (Smith et al, 2009)

In IPA data analysis steps 1-4 are idiographic and it is only when those steps are complete for one transcript that (in step five) the process is repeated for the next case and each case afterwards until all cases have been reviewed individually. It is only at step six that patterns are searched for across cases. Step one involves reading and re-reading the transcript. Time should be allowed in this stage for immersion into the narrative. Smith et al (2009) suggest listening to the audio recording alongside reading as this helps to inhibit the instinct to read and process fast. Taking step one slowly and actively helps the analyst to engage with the participant's world and gain a sense of what was significant to them about their experiences. This step also promotes insight into the interview structure and how narrative was elicited in a way that the researcher may not have picked up during the interview.

Step two is where initial noting begins and it is the most time-consuming and comprehensive part of the process (Smith et al, 2009). Notation should be made on

phrases, semantics and anything that seems of interest. Smith et al (2009) suggest that in reality, steps one and two often occur simultaneously as experience with analysis grows. The focus on notation should be to stay close to the phenomenological intention of representing the participants' world view and experience. Interpretative noting is also undertaken in this stage.

Step three moves from noting to developing emergent themes but the process is still idiographic at this point. By step three, the researcher should be particularly familiar with the participant's narrative and experiences. There should be large amounts of initial noting that need reducing whilst aiming to keep the complexity of (for example) how relationships between experiences and emotions might map together. Smith et al (2009) assert the need to focus down on portions of the transcript as the part and the whole are separated. The researcher aims to turn notes into themes with a descriptive statement or phrase.

The fourth step of data analysis involves seeking connections between the emergent themes. From step three, the emergent themes are mostly likely to be listed chronologically. A process of mapping can take place at this point to plan how the themes might correspond. Potential 'superordinate' themes should emerge in this stage. Smith et al (2009) suggest some techniques for seeking patterns, including abstraction (in which like is put with like and given an overall name for the superordinate theme), subsumption (in which the superordinate theme is already present in reoccurring emergent themes and now comes to the fore), and numeration (taking account of the incidence of which an emergent theme is corroborated).

In the fifth step, the process starts again with the next case at step one onwards, working ideographically. Step six involves the final formal process of looking for patterns across the participant narratives. Smith et al (2009) use the word potent to describe one approach of finding the strongest themes. This means that there is room to give rise to a superordinate theme that is isolated to one narrative if it is strong and important enough. In other instances, there will be similarly arising themes that cross different narratives or distinctive instances that share a similar connection. Themes may be relabelled, and decisions will be made regarding presentation of the themes.

A detailed interpretative reflexive written account should be part of the analytical processes to record thoughts and decisions made (Smith et al, 2009). This structured approach to analysis should facilitate an effective audit trail, adding to the rigour and improving the credibility of findings (Ritchie and Lewis, 2003). Central to IPA is the researcher's ability to make sense of the personal experience (Pringle et al, 2011) and the importance of the researcher's interpretation (Tuohy et al, 2013). Successful analysis is interpretative and therefore subjective (Reid et al, 2005). In IPA, the results should be grounded in examples from the data, co-constructed with participants, and convincing to participants, supervisors and readers (Reid et al, 2005).

4.5.3.1 Participant feedback

Some phenomenological studies include a process of co-production of the themes arising from data collection. Some of this co-production takes place in the interview itself where participant and researcher refine meaning as they discourse. However, there is a more formal process that is considered a potential feature in some types of phenomenological study called 'member-checking' or 'participant feedback' (Bradbury-Jones, Irvine and Sambrook, 2010). The purpose of participant feedback is to take the results of the data analysis back to participants for their views on its accuracy (Bradbury-Jones et al, 2010; Creswell, 1998). Participant feedback is one of the ways in which credibility of a study can be established (Bradbury-Jones et al, 2010). Participant feedback will be discussed with regards to application to this study in Chapter 6, section 6.6.

4.6 Summary

This chapter has outlined the study design and methodological considerations and rationale for adopting interpretive phenomenological analysis to explore the experiences of bereaved parents. The philosophical foundations of phenomenology and the procedures in relation to sampling, and data collection and analysis have been outlined. The next chapter is a presentation of how these methods were applied to the practical undertaking of the research.

Chapter 5 – Application of methods

5.1 Introduction

This chapter presents the application of the methods discussed in Chapter 4, in particular, the use of IPA to undertake the study. The study materials are presented and discussed, followed by application of the procedures undertaken to collect and analyse the data. In addition, the use of qualitative data analysis software and issues of rigour and credibility are discussed.

5.2 Materials

This section details the development of study materials: participant invitation letter and information leaflet, recruitment poster, consent form, and interview guide. Public involvement and engagement are embedded in government policy through the Health & Social Care Act 2012, and patient involvement is good practice when undertaking health research (INVOLVE, 2015). All of the study documents were developed in conjunction with three parents. The parents provided individual verbal feedback on all recruitment materials. One of the parents (a mother) had experienced a neonatal death. The other two parents (one mother, one father) had not experienced a neonatal bereavement. Their purpose in providing PPI was to ensure the appropriateness of the materials and to consider the readability and sensitivity of wording for a study in this specific context. As each item is discussed, the PPI activity and consideration of language are highlighted. The materials were approved by the NHS REC. Study materials are presented in Appendix III.

5.2.1 Invitation letter

Parents were invited to participate in the study by letter and recruitment pack, posted by a person designated as 'Bereavement Lead' in the NICUs on my behalf. One of the local principal investigators in two of the NHS research sites contacted parents by a precursor letter prior to posting the invitation letter. The lead bereavement nurse perceived it to be important to prepare parents for the arrival of the study information pack and to indicate that it related to research and not general communication from R&D department. It may have influenced participant recruitment as there is a

potential risk that parents, having read the first letter, did not bother reading the recruitment letter and pack. This issue is discussed in further depth in Section 5.3.1.

This participant recruitment strategy negated the need for permission to access patient identifiable data since any personal contact details of prospective participants was offered voluntarily by the participants themselves. Researchers who are not in employment with an NHS organisation require permission under Section 60 of the Health and Social Care Act 2012 to access patient identifiable data (DH, 2005). However, in this instance, Section 60 permission was not necessary because the invitation letter included a reply slip and pre-paid envelope so that interested participants could decide whether to get in touch with their information if they wished.

The letter itself was drafted carefully with thought and attention to language. This was particularly important as bereaved parents were the recipients of this letter and mindful consideration was needed to any emotions that could be triggered by the letter. However, it was crucial that the letter stated clearly that the study was exploring events pertaining to the death of their baby and grief experiences. The language needed to be unambiguous yet sensitive. The letter was aimed at prompting the potential participants to want to read more in the participant information sheet. The PPI group was asked to read the letter and consider the language for ease of understanding but also for general sensitivity. Some minor suggestions were recommended, and modifications were then made. Interested potential participants were asked to contact me by phone or email, or to return the reply slip to arrange a mutually convenient time to undertake the interview. The invitation letters from the neonatal unit and the researcher, together with the reply slip are presented in Appendix III.

Optimum timing after the death for delivery of the invitation to participate in the study was difficult to judge because grieving is an individual experience. The rationale for the decision-making process on this was discussed in Chapter 3, section 3.2.2.

5.2.2 Participant information sheet

The participant information sheet was developed from the HRA recommended template (HRA, 2014b) and from reviewing examples of format and content from other researchers. The participant information sheet was produced in booklet form

and is presented in Appendix III. Its content related to the following key areas: explanation of the purpose and background to the research and the reason for being invited to participate, what taking part would involve, what possible benefits there might be from taking part in the research, and the possible risks or disadvantages of taking part in the study. It was important to use sensitive language to convey the purpose of the research clearly and to be honest that participation would mean discussion of the baby's death and parents' personal ongoing experiences. The involvement of parents in the design and wording of the leaflet was fundamental to ensuring that the language would clearly convey the aims, the nature and potential emotions raised by the research, and that it was developed in a way that would cause as little distress as possible (INVOLVE, 2015). In addition, one parent was tasked with ensuring that the participant information sheet was appealing to prospective male participants. I particularly wanted to ensure that fathers would feel equally welcome to the study in order to aid their recruitment.

Readability and the potential literacy level of prospective participants are important issues. Some health research studies are complex in nature, such as phase one randomised controlled trials, and ensuring that medicalised information is understandable to participants is core to informed consent (Gilles, Huang, Skea, Brehaut and Cotton, 2014; Knapp, Raynor, Silcock and Parkinson, 2008). Whilst this study did not require the use of complex research language to explain the nature of the research, it was still imperative to ensure that prospective participants would be able to read and understand the information easily. An online calculation was used to assess for readability, using the Gunning-Fog index (Gunning, 1968). The participant information was calculated at 9.78. An easy average reading level in the UK is nine (Long, 2007). This means that a person who left full-time education after the index calculation could understand the text. For example, an index of 13 means that some educated to the age of 13 should be able to understand the text. Readability checks helped to ensure that information was written so that parents of varied reading abilities were able to understand the study materials.

Before gaining informed consent from each participant, I asked if they understood the participant information sheet. I had a phone conversation prior to the interview with most potential participants, so I had given opportunity previously for any questions to be posed. This opportunity for questions was revisited when consent was gained. All

participants stated that they understood the participant information leaflet, although two parents wanted to clarify points over audio recording and how data would be anonymised. I was confident with the use of PPI and feedback from participants that the leaflet met the desired standard of sensitive and clear information.

5.2.3 Recruitment poster

A recruitment poster was developed to raise awareness of the study. It was designed to be used where bereavement support groups such as Stillbirth and Neonatal Death Society (SANDS) groups were held (Appendix III). Recruitment from these groups was a strategy built into the study design if recruitment from the NHS hospital sites were to prove limited. The poster was placed in the venue where one SANDS group held their meetings. The poster was designed with the aim of capturing attention, and the content was focused on key information aimed to engage potential participants. Contact details were clear, and instructions on how to obtain further study information were provided.

The parents in the PPI group reviewed the poster. Initially the poster did not include an image, but the group was clear that an image was needed to draw attention to the poster. Considerable time was spent discussing an image that would not cause offense or distress, and the parents were firm that it should not represent a baby in any way. The image chosen was a picture made into a sketch image and was confirmed by the PPI group and research supervisor to be sensitive and appropriate. The Gunning Fog index for the poster was higher than the participant information leaflet at 10.92, however this is still within the limits of general readability, and it was decided not to simplify it further. The index rating may reflect that although there were few words on the poster, several of the words had three or four syllables, and the contact information contributed to this. Feedback from the PPI parents was that the poster was suitable and readable. Unfortunately, the poster did not result in any follow-up enquiries. The lead of the SANDS group did not want me to attend in person to speak to the group, and I had no way to know how and where the poster was displayed, or whether parents ever saw it. Therefore, it is difficult to assess if the poster was effective or whether there was an issue that meant that no one enquired about participating after the meeting.

Reflection Point 5.1: recruitment by poster

It is difficult to assess whether the lack of later recruitment related to an issue with the poster itself or if it related to gatekeeping. I was keen to go to the SANDS group and speak to prospective participants there. I offered either to address the group or be available for questions if that was preferred. The lead of the group did not want me to attend and did not explain why. On reflection, I would approach this differently in future, and this is explored further in Section 5.3.1.

5.2.4 Consent form

NHS research governance requires that informed consent must usually be sought from all research participants prior to data collection, and the form must follow the NHS REC guidance (DH, 2005; HRA, 2014). The ethical issues of informed consent were discussed in depth in Chapter 3, Section 3.4.2, therefore this section is focussed on the development of the consent form and how consent was obtained.

The consent form was developed from the exemplars of good practice on the HRA online research support pages (HRA, 2014a). It was reviewed by the PPI group who did not advise any changes. Time was taken before each interview to discuss the study again and to address any questions before going through the items on the consent form in detail. This opportunity allowed assessment of the participants' understanding of the study and the consent form was signed only when the study and potential risks were understood by participants. Consent included agreement for the interview and the sensitive nature of the discussion, subsequent contact for feedback on emergent themes and consent for extracts to be used in conferences, thesis and publications but with anonymity. Permission to audio-record the interviews was given by all participants but one in which consent was given for detailed field notes to be taken instead. Audio recording allowed for active listening, promoted the use of appropriate prompts, and averted the need for note taking which can be off-putting for some participants (Ritchie et al, 2014; King and Horrocks, 2010). Two copies of the consent form were signed, one for the participant and one for researcher.

5.2.5 Interview guide

An interview guide was developed to ensure that the interviews focused on meeting the research aim. The interview guide included 'warm-up' and closing questions, but the main purpose was to ensure a degree of consistency between participants, whilst allowing individual narrative. Further, the availability of having an interview guide can promote interviewer confidence by having reference to documentation and therefore keeping the researcher on track (Ritchie et al, 2014). This was particularly useful in the first two interviews whilst I was gaining confidence in both the researcher role and as a qualitative interviewer. The interview guide is presented in Figure 5.1.

In IPA, the interview guide should not be prescriptive. It should be less detailed than structured and semi-structured interview guides are, as this can limit the development of the participant narrative (King and Horrocks, 2010). This is particularly important in IPA studies in which the interview is designed to facilitate a participant-led narrative (Smith et al, 2009). Consideration was given to 'laddering questions' in the interview guide as suggested by Price (2002). This approach considers the perspective of the participant and the likelihood of working from less invasive to more invasive questions being likely to elicit the most useful data. Following the warm up and initial question, key questions and probes or prompts were intended to be used only as needed. The interview guide had limited content because of the chosen method of an unstructured approach with a greater depth of discussion of salient issues (Ritchie et al, 2014).

Interview Guide

Introduction

Purpose, confidentiality, permission to record/take notes.

Warm-up - Could you tell me about yourself and your family?

Interview Guide

1. Could you tell me about **(name)**?

2. Could you describe your experience when **(name)** was in hospital?

3. Could you explain how things have been for you since you left the hospital?

Prompts
2a. What helped you during this time?
2b. Did anything add to your difficulties during this time?
2c. On discharge were you offered any ongoing support?
Prompts
3a. What has helped you?
3b. What have you struggled with?
3c. Have you been in touch with any support groups?
3d. Who do you talk to on a bad day?

Closure

4. What would you recommend health care professionals could do to support a family in a similar situation?

We are nearing the close of the interview, would you be willing to answer some general questions about you? Age, ethnic group, your occupation and partner's occupation (if applicable).

Reminder – Discuss support strategies after the interview

Figure 5.1 Interview guide

The interview guide was reviewed after each interview in the early stages of data collection to ensure that it elicited data appropriate to meeting the research objectives. No modifications were made to the interview guide. I found that in most interviews I did not ask any questions beyond the rapport building and the first question. I occasionally prompted, but, generally, participants shared their narrative uninterrupted. One exception to this was a couple interview in which it took some time to build rapport and for the participants to feel comfortable enough to share their stories. I was particularly reliant on the first few questions in the interview guide in this situation.

Reflection Point 5.2: reflections on the interview guide

On reflection after data collection was complete, a simplified interview guide would have been better. It was not used in most interviews other than to provide security for me to be sure that the narrative had covered the key areas. In future research, I would not necessarily need prompts in an interview guide but their inclusion was helpful and reassuring for a novice researcher.

5.3 Procedures

This section outlines the procedures related to the recruitment and consent of participants as well as application of data collection and data analysis procedures.

5.3.1 Sample size, recruitment and gatekeeping

As discussed in Chapter 4, a purposive sampling strategy was used. The sample size was originally envisaged to be 20 individual parents. However, the size of the sample was determined ultimately by the end point of NHS REC permission for access to bereaved parents. Slow recruitment for this sensitive research meant that it took the full two years granted for data collection by NHS REC to meet a satisfactory IPA sample size. Seven parents comprising five mothers and two fathers (inclusive of two couples) were recruited.

Reflection Point 5.3: reflecting on sampling and recruitment

The intended sample size was slightly unrealistic in retrospect when related to the practical difficulties in recruitment. Some difficulties had been anticipated but not to the extent realised. Adding in snowball sampling to the purposive sampling technique and building connections with large organisations such as SANDS and the Child Bereavement Charity to advertise the study through their social media may have improved recruitment.

Participants were recruited from two local NHS trusts: one new Level 3 NICU (recruitment centre one) in a district general hospital (DGH) and one tertiary Level 3 NICU (recruitment centre two). The tertiary unit offered a range of bereavement support to all bereaved parents and in this trust, the individual assisting with recruitment was the part-time bereavement team lead. This individual used their own bereavement records to select appropriate prospective participants. In contrast, the individual assisting with recruitment in the NICU in the DGH was a newly appointed part-time bereavement support nurse undertaking a new role within that unit and the admission registry was used to find parents of babies who had died. Both hospital partners adhered to the study protocol, which detailed recruitment procedures and the inclusion and exclusion criteria to select the appropriate recipients. Participant recruitment was initiated by the sending of a recruitment pack, including the invitation letter and participant information sheet.

The two bereavement co-ordinators were direct gatekeepers to the participants. However, there were other gatekeepers in the neonatal unit and this issue was anticipated from the study design stage. Visits to the lead clinicians, lead nurses, research lead, and bereavement support staff of each unit were made early during the design of the study, and before NHS REC and R&D approval was sought. The purpose of this strategy was to strengthen my relationship with those who would be initiating the recruitment and selection process and to take a multi-disciplinary approach to gaining commitment to the study. However, this strategy also built credibility for the study (Shenton, 2004). Further, engaging with those partners early in the process, when the sampling and recruitment design decisions were being made, meant that those partners and gatekeepers could influence the design and suggest mutually agreeable changes. The recruitment partners wanted to influence initial contact time with bereaved parents, and these collaborative discussions influenced the final decisions on initial contact timeframes. Study materials were

reviewed by the all the recruitment partners. The relationships established with the hospital partners were beneficial to agreement when the relevant research and development offices requested the NICUs to assist with recruitment. In the main, the relationships established were helpful and continued to develop.

Reflection Point 5.4: researcher-gatekeeper relationships

There was initial difficulty and reluctance within the team in which I worked previously as a bereavement support sister. There appeared to be a concern and lack of trust about the intentions of what I aimed to study and whether that would threaten the core nature of the work that was being offered by the team. With some lengthy meetings and careful negotiation, the relationship between myself and that team improved vastly, alongside clear information that the study was not finding flaws with the work that was undertaken by the team. I have reflected on those events of relationship difficulty and have surmised that these issues may have been in part related to my change in role outside their team and the potential threat that they felt as a result of that. During and following the study, my former colleague and I maintained a positive working relationship including collaborating on network neonatal palliative care guideline work.

The two recruitment centres used a recruitment tracker to document how recruitment decisions were made and to ensure that prospective participants met the inclusion and exclusion criteria. Each recruitment centre had its own recruitment tracker designed to meet both the study requirements and local documentary needs (Appendix IV). When I requested the information on the recruitment trackers from both NICUs, any identifying names and codes were redacted before sending to me. The recruitment figures presented in the following tables relate to both centres (Tables 5.1 and 5.2). The data relates to numbers of potential participants in the recruitment timeframe, how many recruitment packs were sent out, how many parents were excluded, and the reasons for this. Table 5.3 presents the consolidated recruitment figures.

Table 5.1 Recruitment Centre One – Level 3 NICU

Category	Number
Deaths suitable during recruitment period	59
Recruitment packs sent out	40
Met an exclusion criterion	19
Excluded for coroner's inquest	19
Excluded for language reasons	0
Participants recruited	3

Table 5.2 Recruitment Centre Two – Tertiary NICU

Category	Number
Deaths suitable during recruitment period	57
Recruitment packs sent out	45
Met an exclusion criterion	11
Excluded for coroner's inquest	7
Excluded for language reasons	4
Participants recruited	4

Table 5.3 Consolidated recruitment data

Category	Number
Deaths suitable during recruitment period	116
Recruitment packs sent out	95
Met an exclusion criterion	30
Excluded for coroner's inquest	26
Excluded for language reasons	4
Participants recruited	7

A significant number of potential participants were excluded due to ongoing coroner's inquest, but fewer were excluded for language reasons than expected. There were other NICUs in the north-west region that could have been included as recruitment centres and would be considered for future research. There would have been limited benefit in including the Level 1 and 2 units, as deaths on those NICUs are rare. Consideration of the recruitment data was helpful to reflect on the causes of the recruitment difficulties. However, it will always be difficult to recruit participants to bereavement research (Currie et al, 2016).

All respondents to the participant information were mothers, and all mothers included in the study had a partner at the time of death and interview. Mothers were asked if their partner wished to be involved, and interview days and timings were offered to fit in with any work or family commitments. It was anticipated during the study design phase that fathers might be less available to participate in the research due to work commitments, whereas some mothers might still be on maternity leave, sick leave, or not have work commitments. For some participants this proved to be the case, however one mother returned to work after eight months and was interviewed after being back at work for one month. All fathers were in employment, but some were able to make the time to be interviewed.

5.3.2 Data collection

Data were collected using unstructured interviews and the following section presents the approach used, including the communication skills required, the stages of the interview, how questions were planned if needed, factors involved in interviewing couples, and field notes.

The principles and practice of good communication skills and establishing therapeutic relationships can be applied in qualitative research interviewing (King and Horrocks, 2010; Ritchie et al, 2014; Streubert and Carpenter, 2011). Building rapport is essential to gaining the trust of participants and it is a core component of qualitative interviewing. Aspects of the core conditions of building therapeutic relationship are transferable to the researcher-participant relationship: congruence, empathy, and unconditional positive regard (Rogers and Freiberg, 1994). Congruence means that the researcher is genuine with the participant, and congruence is essential for mutual trust and disclosure. Empathy refers to being able to feel what it might be like for another person, and this concept is vital in interpretative phenomenological methods in which the hermeneutic circle requires the researcher to be able to come around to the participant's viewpoint (Chan, Brykczynski, Malone and Benner, 2010).

Unconditional positive regard is appropriate because the researcher should not judge the participant, and participants should feel able to trust the researcher enough that they can narrate their story without feeling judged (Rogers and Freiberg, 1994).

Whilst the researcher-participant relationship is not a therapeutic relationship, nurse researchers can use their experience and skills in therapeutic relationships and

communication to create successful rapport and trust with participants. The communication skills that I had as a bereavement nurse were vital to my ability to conduct an interview about such a sensitive and emotive subject.

Researchers undertaking sensitive research have a need to be compassionate and to appear to be so by participants (Dickson-Swift et al, 2007). It is essential to sensitive research that researchers can care for the participant during the process. Some examples of caring that researchers might be expected to demonstrate are compassion, comfort, concern, empathy, enabling, interest, involvement, sharing, support, and trust (Currie et al, 2016; Dickson-Swift et al, 2007). These approaches needed to be balanced with the professional boundaries expected of registered nurses, and appreciation was essential of the differences between a therapeutic relationship and a researcher-participant relationship (Dickson-Swift, James, Kippen and Liamputtong, 2006; NMC, 2018; Roberts, Fenton and Barnard, 2015). Professional boundaries, however, should not be obstructive or indicate detachment from the participant. Dickson-Swift et al (2006) explored the experiences of 30 qualitative researchers who studied sensitive topics; the sample including both novice and experienced researchers. The findings suggested that there could be difficulties in establishing the difference between a research interview and therapeutic relationships. Additionally, the potential implications for poor boundary management were explored, and findings included emotional exhaustion, burnout and detachment (Dickson-Swift et al, 2006).

Reflection Point 5.5: moving from a therapeutic role to a researcher role

It was a new experience to move from a nurse-parent relationship to a researcher-participant relationship. When I worked as a bereavement nurse, I was familiar with visiting parents and having knowledge of their backstory and their baby's end of life journey. It was different to start building rapport without that information but not difficult. For this reason, I had fewer preconceptions going into the research setting. I had to purposely 'bridle' any preconceptions relating to the care and decisions that parents discussed as it would have been easy to make assumptions about why things had happened, when that would not have been appropriate. I reminded myself to focus on the parents' experience and viewpoint. The concept of 'bridling' is discussed in Chapter 4.4.2.

Building rapport and trust with participants had to be planned, and scenarios needed to be anticipated, whilst being flexible, spontaneous, and congruent. When building

rapport, I explained to participants that their honest experiences were what was sought and that there were no expectations regarding the content of their narrative. Nurse researchers can draw on their communication experiences and training to aid their skills in eliciting data. I found that I utilised all my skills and experience of communicating with bereaved families during the interviews.

Ritchie et al (2014) described six different stages of qualitative interviews, presented below:

1. Arrivals and introductions
2. Introducing the research
3. Beginning the research
4. During the interview
5. Ending the interview
6. After the interview

While laddering of questions was considered, the nature of the narrative was open and unstructured and for most parents; therefore, laddering was not adopted. Some parents spoke about the most difficult aspects early in the interview; it was their prerogative to approach their story in any way they wished.

The relationship between participant and researcher begins immediately, and in this study during the initial telephone contact but the start and finish of interviews are particularly significant (King and Horrocks, 2010). The start of the interview sets the tone for trust and rapport, and introductions and small talk can help relax nervous participants. I was in the participants' homes in most cases; nevertheless, the onus is on the researcher to initiate conversation. Following introductions, questions about the study and formalities of informed consent (stages one and two), the interview could begin. The interview guide was developed with a warm-up question, "Could you tell me about yourself and your family?" This question aimed to ease participants into the difficult research topic. The warm-up question was designed to allow participants to give an easy, descriptive response that would relax them into the process; this appeared to work well with all participants.

In stages 3-5 of the interview, the participants were given a verbal indication of moving on to that section, for example, 'I'm going to ask you about your baby now.'

This helped the participants to know what to expect and may have put them at ease considering the nature of the research topic. Stage three is the crucial section of the interview as this is where the research aims and objectives are met. As interviews were unstructured, the questions on the interview guide were not often utilised. However, all questions and prompts that were used were open questions designed to facilitate narrative. There were no leading questions, and closed questions were used rarely (Figure 5.1). For some participants, the first question, asking about their baby, led to the whole narrative with little need for prompt or interjection. For other participants, who were less relaxed, all three questions and additional prompts were used. The interview guide provided direction in those instances.

In the situation of sensitive research, when the narrative has been emotional and powerful, ending the interview takes thought and planning and should not be rushed. An abrupt ending can affect the researcher-participant relationship and could potentially affect retention of a participant in the study. In addition, indicating that the close of the interview is imminent can prompt the participant to raise anything not yet discussed (Ritchie et al, 2014). In the seven interviews conducted, this transition with the prompt 'is there anything else you would like to tell me?' often started a further section of narrative. As the interview closed, there was an ease from monologue to dialogue with a return to social interaction. Once the interview had finished, and audio recording had ceased, participants were thanked and brief discussions regarding data and reporting were exchanged. Fundamental to this study, time was spent discussing the emotions that might arise after the interview and the availability of support for participants afterwards. Participants were given written information on support services they could access after the interview (Appendix III).

The interviews for this study were planned to take approximately 60-90 minutes, and it has been suggested that most of the relevant data can be collected in this period (Hansen, 2006). The interviews took between 50 minutes and three hours. Three hours is excessive according to the literature (Hansen, 2006), however this interview was a traumatic narrative and new data arose throughout the three hours (as discussed in Chapter 3, Section 3.3.1.2).

Reflection Point 5.6: dealing with a long and emotive interview

The parent who had a long interview had the desire to tell her story to completion, and she repeatedly said that she wanted to continue. Breaks were offered and taken, refreshments were used, and the parent stated that it had been 'good to get so many things off her chest'. She kept thanking me for listening. I discussed my management of this long interview with one of my supervisors who agreed that it was appropriate to have continued under the circumstances, as any distress was managed, and the parent wanted to continue.

This interview was also the subject of an urgent clinical supervision appointment because the narrative had been traumatic in nature and upsetting for me to hear. I wanted to talk through my feelings about this interview and check through supervision if there was anything to reflect on and from which to learn for future interviews.

The date and times of the interview were held at the convenience of the parents; however, this was limited by restricting timings later in the evening to ensure the safety of the researcher as discussed in lone working, Chapter 3, section 3.3.2.

Early review of interview technique was undertaken after two interviews. Transcripts and reflection on the interview itself were discussed with a supervisor to assess the effectiveness of the interview technique and whether any amendments were needed to the procedures. No refinements were necessary, however, it was useful to hear my own interactions during transcription. From this, I modified my interview behaviour to be less vocal with sentences and use more affirmations 'mmm' and 'yes' with non-verbal nods and facial expressions. I also realised that it was possible to probe more with little interruption using phrases like: 'Can you tell me more about that?' or 'Then what happened?' I utilised these slight modifications as I moved into interviews 3-7.

Reflection Point 5.7: settling into the researcher role in interviewing

The first research interview that I undertook yielded rich data, but it was the shortest interview, and on reflection, there were areas that I could have explored further. I can remember feeling particularly conscious about not talking too much and just letting the unstructured interview unfold, but also being concerned about the audio recorder capturing everything. I was also anxious about being able to meet the research aim and objective and had the interview guide in my view all the time.

By the second interview I was more relaxed about meeting the research aim and being able to let narrative unfold. I was not worried about the mother not wanting the interview to be audio recorded, I took notes quickly, and some shorthand knowledge helped with that. However, reading back over the transcripts, I could still have probed a little more.

From the point of the rest of the interviews, I was satisfied that I had probed sufficiently when needed, however, overall, the narrative in all the interviews unfolded naturally, with minimal structuring by me.

5.3.2.1 Interviewing couples

This study aimed actively to interview both mothers and fathers so that a range of views were represented, identifying shared and differing experiences and perceptions. Fathers' experiences and feelings can be marginalised in perinatal and neonatal deaths, and their social role of supporting their grieving partner is most commonly described (Badenhorst, Riches, Turton & Hughes, 2006). Furthermore, studies have shown men and women to have differing attachment and grieving behaviours, hence the need to capture not only differing individuals' experiences but also different experiences by gender (Benfield et al, 1976; Rubin, 1976; Valizadeh et al, 2013). Strategies to encourage the recruitment of fathers included ensuring that the participant information leaflets were appealing to fathers as discussed in section 5.2.2.

Interviews were undertaken either individually or as a couple, according to the preferences of the participants. This enabled participants to decide the most comfortable format on an individual basis. It is possible that some participants felt more secure in a research interview situation with their partner with them. However, it was more difficult at times to analyse the individual experience, this is discussed further in transcription and data analysis.

5.3.2.2 Interview companions

Two of the interviews undertaken for this study were observed by companions not participating in the actual interview. This is a common occurrence for researchers who undertake interviews in the home, especially when participants are vulnerable (Sivell et al, 2015). However, the companions during data collection in these cases were children. During one interview, when a couple was being interviewed, their children were present. The parents were interviewed at the weekend so that the father could participate, however they had three other children. The mother had informed me prior to the interview that her two youngest children (under four) would be present during the interview. Parents ensured that their children were occupied with games and TV. Neither of them listened to our interview, nor did they seem to have the comprehension to understand or be affected by the content of the discussion. However, later in the interview, the teenage child came down to the living room where the interview was held and listened to what was being discussed. The child did not seem distressed, however, he appeared emotionless which indicated that he could be masking his emotions. I felt concerned about what the child was hearing, but, on reflection, this may have prompted discussion between them all later. To deal with any repercussions arising from this child witnessing the interview, when I went through the support strategies afterwards with the participants, I also pointed out which support organisations had support for children and teenagers. Initially, I was uncomfortable with the interview narrative being witnessed by a teenager who was already grieving the loss of his sibling, but the participants appeared content for the child to remain and they had to be allowed to know what was best for their child.

In the other instance, a participant had their infant in the room during the interview, however, this did not cause concern as the infant did not have the cognition to understand the content of the interview. Holding the infant at times when emotions were difficult appeared to offer comfort to this participant.

5.3.2.3 Field notes and journaling

A notebook was used during each interview to record pertinent information that related to the interview. This was utilised for full note taking in interview two where the participant declined audio recording. In the rest of the interviews, I occasionally noted down a comment or phrase that seemed of prominence. These notes were

more about my reactions to what were said as the recordings captured everything else. Field notes were used sparingly in the interview, but I drove away from the participants' houses and then parked nearby, making initial reflections on that interview. Initial reflections captured a sense of the participants themselves, but mostly my initial thoughts about the interview and content. Analysis and interpretative thoughts started from this point.

A reflective journal was kept throughout the study, however, from data collection onwards journaling was more regular. I recorded reflective thoughts in relation to the data itself, analytic and interpretative thinking. The development of the visual tool presented in Chapter 6 evolved through the journal. The journaling continued until thesis completion.

In summary, data collection was in the form of unstructured interviews. Interviews were planned and undertaken with consideration of the rapport-building and communication skills needed to promote disclosure. Unexpected difficulties in the interview have been discussed and the use of field notes and journaling to the data collection process have been recognised.

5.3.3 Data analysis

This section will discuss how data were analysed using IPA. First, the approach to transcription is discussed.

I undertook transcription of the data personally. Audio recording was of high quality for all the interviews that were recorded, and this aided transcription. King and Horrocks (2010) present a range of decisions that need to be made regarding transcription, including who transcribes, verbatim or partial transcription, whether to tidy up narrative or not, and whether a system of transcription will be used. The decision to transcribe personally was made not only so that I had the experience of transcription as a novice researcher but also so that I could remain close to and connected to the data. Smith et al (2009) suggest that transcription does not need to detail non-verbal exclamations or pauses because the aim in IPA is to interpret the meaning of the narrative. A full verbatim transcript was undertaken in each case and it was important to note the emotions of participants on the transcript, for example when they were crying or if a pause was taken to deal with emotions. The verbal

expressions such as 'umms' and 'erms' were not transcribed but a hesitation note was added if appropriate. No corrections were made to the colloquiums or swearing vocabulary used by participants. Transcription of couples' interviews were made of both contributions together initially, and then separate individual transcripts were made for each parent to facilitate an idiographic approach to analysing that parent's narrative. Davidson (2009) suggests that a clear description of how transcription is undertaken is imperative to the trustworthiness of the data as the transcript is not only used for data analysis, but it is used as evidence of the analysis.

At first, transcription was undertaken soon after the interview. After realising the psychological burden of moving straight from the interview into long hours of transcription, this was delayed and undertaken in stages for later cases. Issues relating to transcription burden are discussed in Chapter 3, Section 3.3.1.1.

The robustness of data analysis is central to the credibility of qualitative study findings and ensuring the research aims are met. Data analysis was lengthy and intense, taking place over several months. The six-step approach detailed in the previous chapter was followed. Allen and Eatough (2016) suggest that as the stages of analysis are navigated, that there is a move from the particular to the shared and from the descriptive to the interpretive. Using Smith et al's (2009) stages and detailed guidance enabled a systematic approach to data analysis and drew on several strategies, which are now outlined.

The first step of data analysis involved an idiographic and focused, line-by-line analysis through reading, concentrating on the experiences of the participant as the central focus as suggested by Smith et al (2009). I worked on each narrative in isolation and the gaps between interviews helped to think about the participants' individual narrative and unique situation. The process began with transcription, and analytic thoughts began to emerge. This was achieved by reading the transcript through many times, and I listened to the audio recording twice whilst reading the transcript. This dual approach brought inflections of words and emotions to the fore. Later, reading on paper caused phrases and words to 'come to life'. Smith et al (2009) suggest that the reading and re-reading of transcripts can bring the building of rapport into focus, and this successful building of relationship between researcher and participant can then lead to areas of richer data. I was able to identify this with

participants 1, 5, 6, and 7, when, as they began to trust me more, they disclosed more about their private experiences. I did not identify this during the interview because that was often fast-paced. However, when reading the transcripts, it was more easily identifiable.

Initial analysis of an individual participant's responses (who was part of a couple being interviewed together) posed a new challenge because of how the dialogue between the couple was so interlinked. The transcripts were separated into each participant, but a joint transcript was always kept in view so that I could follow the thread of the participants' experiences, their affirmations, corroborations and disagreements. It was a challenge to keep an idiographic approach through all the stages of analysis including reading then noting, and so the noting and later analysis for these participants took longer than other analysis of transcripts.

The narrative journeys of each participant were not linear. I found this to be an issue that I had to overcome during step one of data analysis. The individual participant narrative of their baby and their own experiences of events, emotions, and feelings were conveyed often in a chaotically structured story. Nevertheless, at the time of the interview, it was not difficult to follow the thought pattern of individual participants, though at times this was more difficult after transcription. Listening to the audio-recordings again while reading the transcripts helped to contextualise the move from one experience to another, this was aided by developing the parent portraits presented in Chapter 6, Section 6.2. When parents talked about their baby in one context, this often led to how they thought about it in their grief journey, and it could take some time to return to the events before and during the end of the baby's life. As I analysed the findings for each participant and as more participants were added to the analysis, I became more used to the complex thought patterns of the participants and was able to adapt to putting the pieces of the story together and in order.

Step two continued to be an idiographic process and involved making initial notes and comments on the transcript. I used underlining as a supplementary technique at this stage. This noting was a time-consuming task, especially with the first three transcripts, as I was learning the skills of IPA. This became easier with later transcripts as I felt more familiar with this step and its purpose. The notes and comments were initial analytical observations, thinking about how individuals were

making sense of their experiences. Smith et al (2009) suggest a free text approach to noting, in which some parts may not require comment and others can create copious notes. This did not feel intuitive as I felt a desire to label 'units of data'. How comments were phrased at this point was not important, but capturing the significance or emotion of an experience was. Smith et al (2009) indicate that there is a need to stay close the participant's meaning, keeping a phenomenological lens, and I kept this in mind as I made comments in initial noting. In this stage, initial noting normally includes descriptive comments when narrative moments are taken at face value and conceptual comments which might take the format of questions. I used both techniques to facilitate my thoughts in this stage.

Once I had finished initial noting for the first participant, my supervisor reviewed it with me. I received guidance about where some further initial noting was needed. This supervision further developed my knowledge of the process and enhanced the manner in which I approached the later transcripts in these stages. Supervision relating to data analysis, debriefing of the process, and peer scrutiny of analysis are crucial to credibility and overall rigour of the study (Shenton, 2004; Thomas and Magilvy, 2011).

Step three involved identifying emergent patterns in the data by examining convergence and divergence as well as areas of significance (Eatough and Smith, 2006). I was intimately familiar with the individual interview by this stage, and the purpose was then to reduce the volume of detail in noting. Initially, this seemed to be a difficult task: to decide what was prominent and thematic rather than just noting. It is suggested that discomfort at this point is usual but that this is when the researcher begins to manifest the hermeneutic circle, moving from the part to the whole and back (Smith et al, 2009). There is potential tension here with the 'double hermeneutic' in which consideration is needed of the potential for the participants and the researcher to view the phenomenon of participants' experiences differently (Wagstaff, Jeong, Nolan, Wilson, Tweedle, 2014). However, through returning to the data when participants were making sense of their own experiences, I was able to direct interpretations and decisions towards participants' experiences. As I worked on discrete chunks of data, this aided my progress, moving from the part then to the whole. Wagstaff et al (2014) described the satisfaction gained from knowing and understanding the complex identity of a participant, and this resonates with my

experience of each participant and the growth of knowledge through connection with the narrative in the transcript. An iterative process was adopted to go back and forth across the data, linking themes to quotations. Further, this process is one in which there is a move from being participant-led to the researcher becoming more central. Again, this felt uncomfortable. Smith et al (2009) assert that the interpretative element of IPA needs to be emphasised at this point. The beginning of the sub-themes presented in Chapter Six began to emerge (although the wording had not yet been refined). The aim was that emergent themes would represent not only the participants' words, thoughts, and feelings but also my interpretation as the analyst (Smith et al, 2009). Insider (participant) and outsider (researcher) perspectives also converged visibly in this step (Reid et al, 2005).

As analysis progressed in step four, a structure was needed to demonstrate how the themes were related. Themes were initially ordered in the chronology of when they arose in the transcript, these had to be developed into 'a map' of how they fitted together. This was a repeated process, and, initially, I lacked confidence in this stage. I adopted a rudimentary process of cutting up the themes and moving them around to try to gain focus. A process of abstraction was applied where individual patterns were identified between themes. Superordinate themes can be developed in this stage, finding like-for-like ideas and assigning a name for that theme. Early in this process, it was clear that grief and isolation were moving to the fore of my thinking and appeared to be central across parents' narratives. However, there was also a range of other emergent themes between which I was searching for potential connections. At this point, it is suggested that oppositional themes should be considered, as this can sometimes allow for further organisation. For example, communication experiences and support experiences seemed to be in opposition, and seeing the opposing view brought more focus. An alternative approach that could be considered are numeration, considering function and theming using CAQDAS (Smith et al, 2009). I attempted numeration of theme frequency, but it appeared to be a quantitative approach and a tallying of numbers. Despite guidance for this in Smith et al's text, I did not persist in this.

Step five was concerned with moving onto the next transcript, where the process is repeated. No two analysis experiences were the same, and participants had different end of life experiences with their baby and individual moments of crisis. It is

suggested that initial bridling of the previous transcript experiences allows for the individuality of the next transcript being analysed (Smith et al, 2009). I tried to do this and, because of the differences between participants' stories on initial noting, I was able to set aside preconceptions of what might be thematic. However, it is unavoidable that some influences from previous transcripts will arise and Smith et al (2009) suggest that this must not halt new themes from emerging. As my experience grew with the technique, moving back and forth between the steps was not any faster but I grew in confidence with the process.

The final step of looking for patterns across the narratives was the ultimate purpose of data analysis and there was anticipation to undertake step six. At this point in the analysis, I became more removed from the emotions of the transcripts; it had transformed into theoretical work. Themes were connected between transcripts, and substantive themes continued to evolve further, from which related sub-themes then emerged and vice versa. The approach of using the hermeneutic circle was engaged again, moving from the part to the whole iteratively, and further consideration of potential tensions with the 'double hermeneutic' were part of the interpretative processes and decision-making. The process included examining the transcripts for commonalities of emergent themes, looking for connections, recognising when patterns were emerging, and searching themes that were the most powerful. In IPA, a powerful theme from one participant can still become a superordinate theme (Smith et al, 2009). Wagstaff et al (2014) deliberated the dilemma that can arise in IPA related to individual as opposed to common themes and how researchers navigate this tension. The steps of IPA data analysis take an idiographic approach until the final step when patterns are searched across the narrative in a nomothetic approach. In this thesis, for example, descriptive and interpretative notes related to resuscitation conversations and returning to NICU did not arise across all of the participants' transcripts. However, it was a powerful theme that became a subordinate theme in the findings. Conversely, grief and isolation were prominent and powerful in all the transcripts. Emphasis was given to an idiographic emergent theme when it was powerful though not common to other participant experiences.

Shortly after my work on step 6, I sought supervision and we spent time with the transcripts together reviewing the connections, themes, and patterns. During this supervision, the initial concept for a visual tool from the idea of a black hole or a

sandstorm was discussed (presented and discussed in Chapter 6, section 6.8). The process of seeking peer scrutiny, supervision, and debriefing at this second point in the data analysis demonstrates the provisions made to seek credibility in the study and provides a means of audit of the processes taking place (Thomas and Magilvy, 2011; Larkin and Thomson, 2012). Following on from supervision, analysis continued, seeking patterns and deeper interpretation of descriptive and interpretative comments, and an initial findings structure emerged. The findings presented in Chapter 6, section 6.3 continued to be refined over months after finishing the six steps of IPA, as the analytical process particularly in relation to the interpretation into a visual tool was finalised. Arguably, this refinement of the visual tool was still part of step six.

5.3.3.1 Qualitative data analysis software

Computer-assisted qualitative data analysis software (CAQDAS) can assist with some of the tasks of data analysis, allowing modification, potentially eliminating writing coding on transcripts and aiding management of large data sets (Gray, 2014). However, the researcher's decisions remain central to the credibility of the analytical processes, and coding must be undertaken by the researcher as it involves reasoning and decision-making (Ritchie et al, 2014). Criticisms of CAQDAS suggest that it can distance the researcher from the data, and that the pace and ease of the software can lead to researchers cutting corners (Ritchie et al, 2014). Further, it has been suggested that deep and careful data analysis can be secondary or even absent in the desire to code and manage large data sets (Gibbs, 2013).

In this study, CAQDAS enabled the initial organisation and storage of information, when multiple versions of data were stored and accessed in early theme development. Caution was exercised in relation to coding to avoid 'coding-fetishism', by which novices can become carried-away coding the less relevant with the prominent (Gray, 2014). There must be further caution applied when using CAQDAS in IPA because of the value placed on each separate participant narrative. If emphasis is made purely on coding and aligning themes through comparison across other transcripts, then co-construction of meaning with participants may be lost and the philosophical foundations of IPA could be diluted (Crotty, 1996; Holloway, 2005).

Streubert and Carpenter (2011) suggest that training with the selected CAQDAS is vital before data analysis in this format. I undertook 1.5 days training on NVivo before attempting to analyse the data. I was limited to NVivo as this was the software licenced to the university, but it is possible that alternative CAQDAS would have facilitated IPA analysis more easily. NVivo was used initially to code but the tendency to over-indulge in this was present and so a transition to paper-based noting and commenting was made. Discussion with other IPA researchers revealed that this is a common experience and that researchers using IPA sometimes do not use CAQDAS. Smith et al (2009) suggests that stages 2-3 of IPA data analysis work most effectively with a hard copy. CAQDAS was of limited use, and hand-coded data analysis took precedence in this study. This was feasible and practical due to the reasonable volume of transcribed data. CAQDAS is an approach that I would like to use further in the future.

5.3.3.2 Participant feedback

This study was designed to utilise a form of member-checking or participant feedback to increase the trustworthiness of the study as part of the methodological processes. This is congruent with some interpretive phenomenological study designs (Bradbury-Jones et al, 2010). The purpose of this was not to collect more data but to gain feedback on the initial findings. Participants were sent a simple copy of Figure 6.1 in Chapter 6 with a covering letter asking for feedback either by return of mail, email, or by telephone with their thoughts on the findings and any inappropriate wording. I did not have any replies to this request. After discussion with supervisors, this request was not made again. It was not possible to anticipate what participants were going through in their lives at the time they received this request; for some it had been almost two years since their interview. It was clear that participants did not want to engage any further with the research, however there was no request to withdraw at any time.

Member checking is not a mandatory part of the methodological process because the findings are more than descriptive; they are interpretative. Studies with a single case design are most appropriate for this type of validation (Larkin and Thompson, 2011). The findings went through peer validation from supervisors and one of the recruiting bereavement teams.

5.4. Rigour and trustworthiness

Rigour and trustworthiness can be demonstrated from study design through to discussion of findings. Lincoln and Guba (1985) suggested four quality criteria for establishing trustworthiness: credibility, transferability, dependability and confirmability. Transferability is discussed in Chapter 8, section 8.3 in implications for practice, research and policy. An in-depth methodological description and discussion would allow this study to be repeated and it allows integrity of the results to be assessed. These two elements offer provision toward dependability and confirmability respectively. Further, confirmability relates to recognition of limitations of the study, which are discussed in Chapter 7, section 7.2.

Credibility has been discussed through the supervision process utilised in the steps of data analysis, but other areas were also considered. Further provision for credibility was made by consideration of the following: using a recognised research method (Chapters 4, 5, 6 and 7), early familiarity with the culture of participating organisations (Chapters 4 and 5), tactics used to promote honesty in participants' narratives (Chapters 5 and 6), iterative questioning (Chapter 5, 6 and 7), frequent debriefing (Chapter 5, 6, 7 and 8), peer scrutiny (Chapter 5), reflective commentary (Chapters 5 and 6), background, qualifications and experience of the researcher (Chapter 1, 6, 7 and 8), thick description of the phenomenon (Chapter 6), examination of previous research findings (Chapters 2 and 7) (Shenton, 2004). In addition, reflexivity reported through the use of text boxes has documented my thoughts and progress through the journey of undertaking this study.

The structure and detailed description of design, methods, procedures and findings provide an audit trail for how the research was undertaken, how decisions were made, critical thinking and how analysis was undertaken. These elements help to establish the authenticity and trustworthiness of the data and study as a whole (Streubert and Carpenter (2011)

5.5 Summary

This chapter has presented and discussed the application of the methods considered in Chapter 4. The application of the method was an iterative process and, therefore, not all methods were applied how they were planned. Flexibility and reconsideration of methods were needed at times to ensure the best approach for contacting, recruiting, and interviewing participants. Data analysis were undertaken using the steps described by Smith et al (2009) but with some flexibility to allow creativity and interpretation. The findings that emerged from the application of the methods are presented in Chapter 6.

Chapter 6 – Findings

6.1 Introduction

This chapter presents the study findings in four superordinate themes that emerged from the analysis of parents' narratives: 'the enormity of grief', 'being isolated', 'trying to survive' and 'routes to an improved future'. Explanations of the findings will be offered in Chapter 7. A visual tool, 'the Neonatal Grief Sandstorm' will be offered as a way to represent parents' experiences of these difficult events. First, parent characteristics will be presented alongside 'parent portraits' with a summary of each parents' journey during and following the death of their baby.

6.2 Parent characteristics and portraits

Seven parents participated in the study, comprising of five mothers, two fathers and including two couples. All the participants were in heterosexual relationships, therefore any differences that might occur in homosexual couples and their experiences and grieving behaviours are not be represented in this study. The participants' ethnicity was 'White British' however, they were from a diverse cross-section of social class. Issues of heterogeneity and homogeneity are discussed in further depth in Chapter 7, Section 7.2. The participants' babies died as a result of a diverse range of congenital abnormalities, complications of extreme prematurity, complications due to maternal/delivery problems and infections. The specific causes of death are presented in Figure 6.1.

Cause of death	Numbers
Infection and SDLD	1
Placental abruption leading to HIE	1
Necrotising Enterocolitis	1
Exomphalus and suspected genetic abnormality	1
Antepartum haemorrhage leading to HIE	1

Figure 6.1 Causes of neonatal deaths n=5

A brief explanation of the cause of death is provided to add background context. One baby died from a combination of an overwhelming sepsis (positive blood cultures)

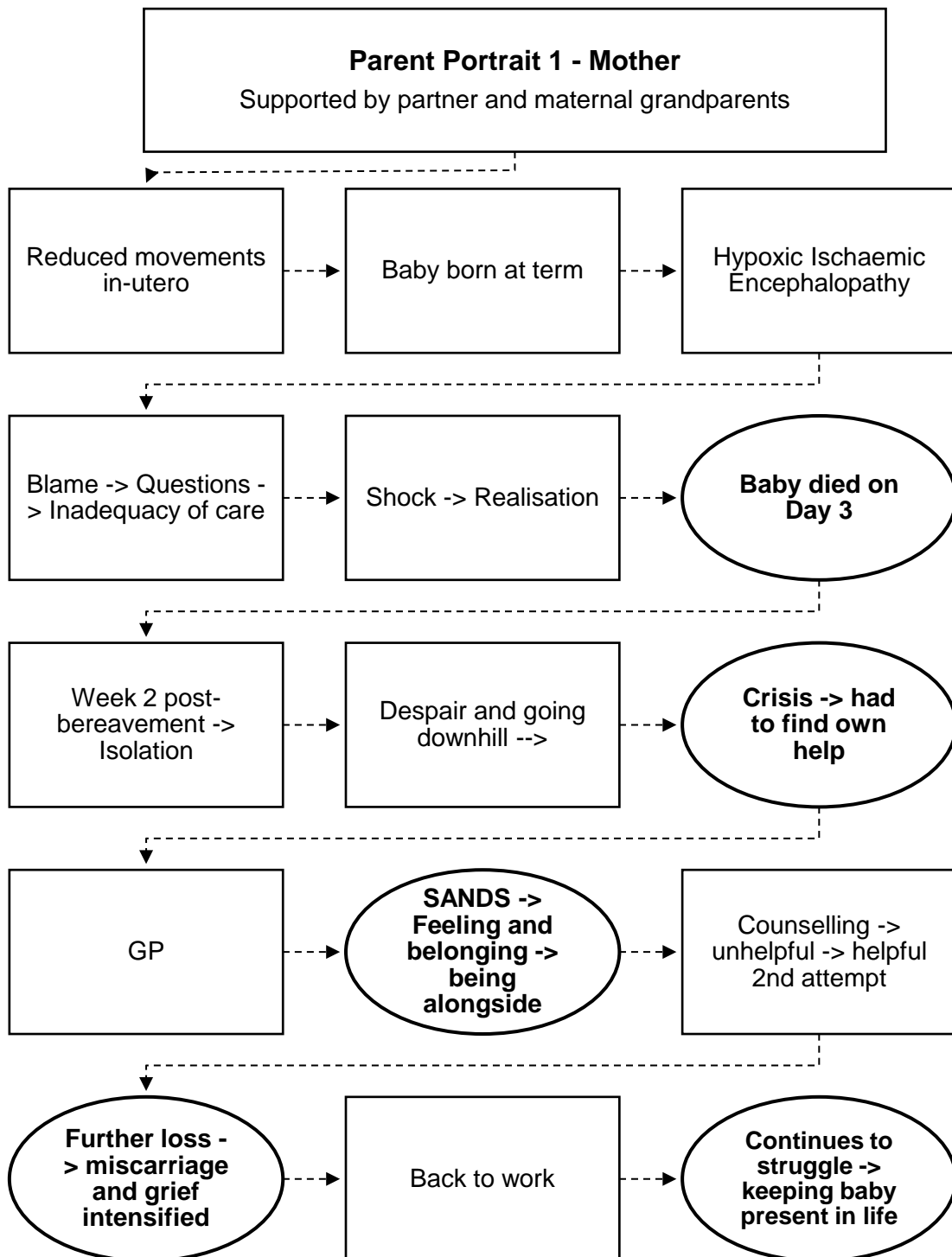
alongside Surfactant Deficient Lung Disease (SDLD). SDLD is one of the most common complications of prematurity, where the immature and undeveloped lungs of the premature infant lead to difficulty with gaseous exchange and lung expansion due to the lack of surfactant production in the lungs (Barnard and Weaver-Lowe, 2016b). Another baby died as a result of an undetected maternal placental abruption, resulting in foetal hypoxia and development of neonatal Hypoxic Ischaemic Encephalopathy (HIE). HIE is where a lack of oxygen to the brain causes untenable brain cell death and it is graded one to three, where grade three represents the most severely affected babies (Levine, Tudehope and Sinha, 2008). In this case, the mother's placenta detached from the uterus prior to labour.

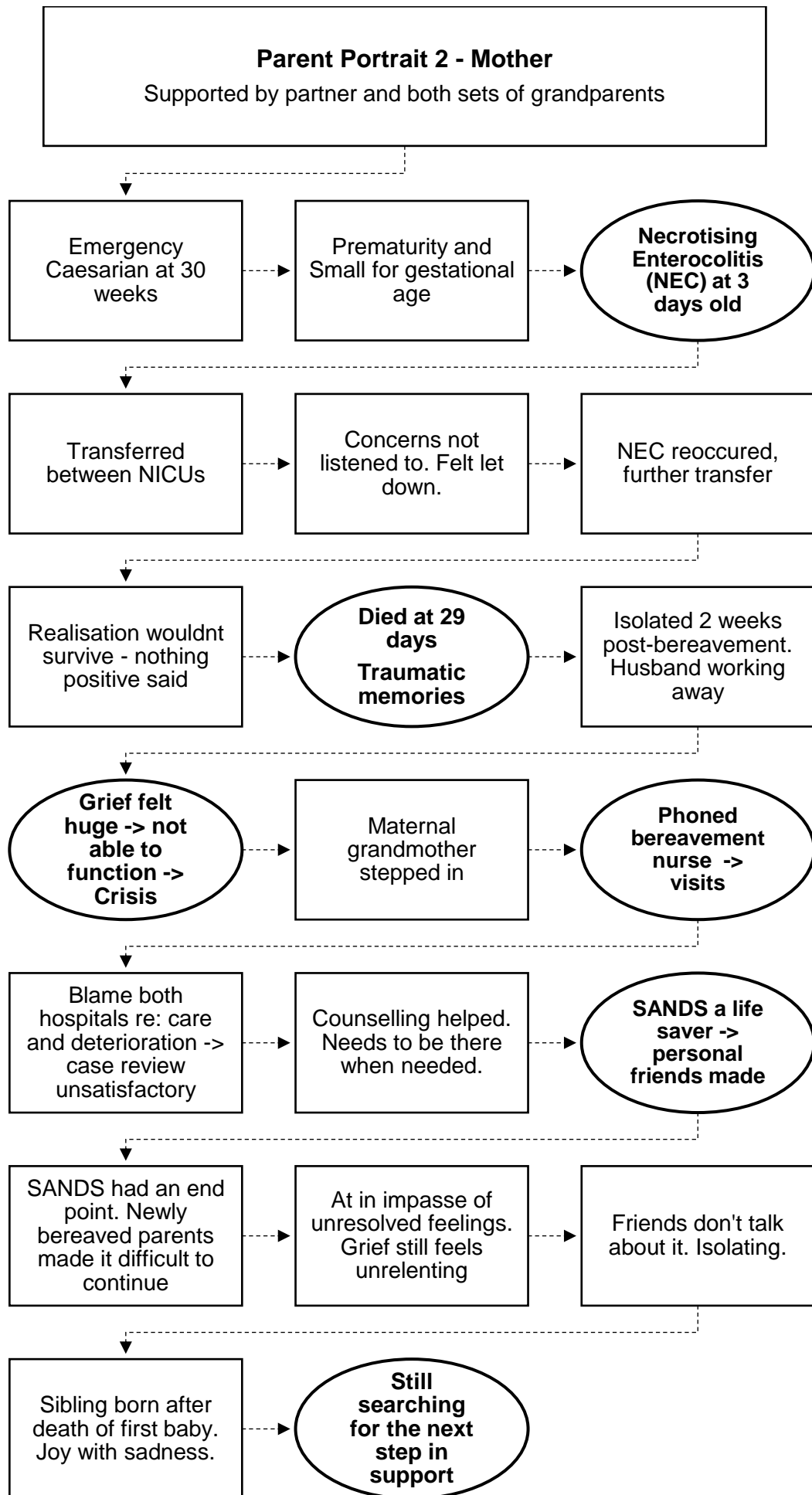
Another baby suffered a similar outcome where the mother had a low-lying placenta and proceeded to experience an antepartum haemorrhage (APH), leading to foetal hypoxia and neonatal HIE. APH is bleeding from the birth canal after the 24th week of gestation (Royal College of Obstetrics and Gynaecology, 2011). A further baby experienced a known complication of prematurity called Necrotising Enterocolitis. This is an infection and inflammation in the immature neonatal intestine that progresses to necrosis (Levine et al, 2008). Many babies can be treated successfully conservatively and recover, but for some babies, the infection advances very quickly and becomes life threatening. Another baby was born with a congenital abnormality called an exomphalus, where the baby's internal abdominal organs herniate into the umbilical cord in-utero (Tucker-Blackburn, 2013). Often, this abnormality is repaired by surgery and infants recover successfully, but it can be associated with genetic malformations and be life threatening, as it was in this case.

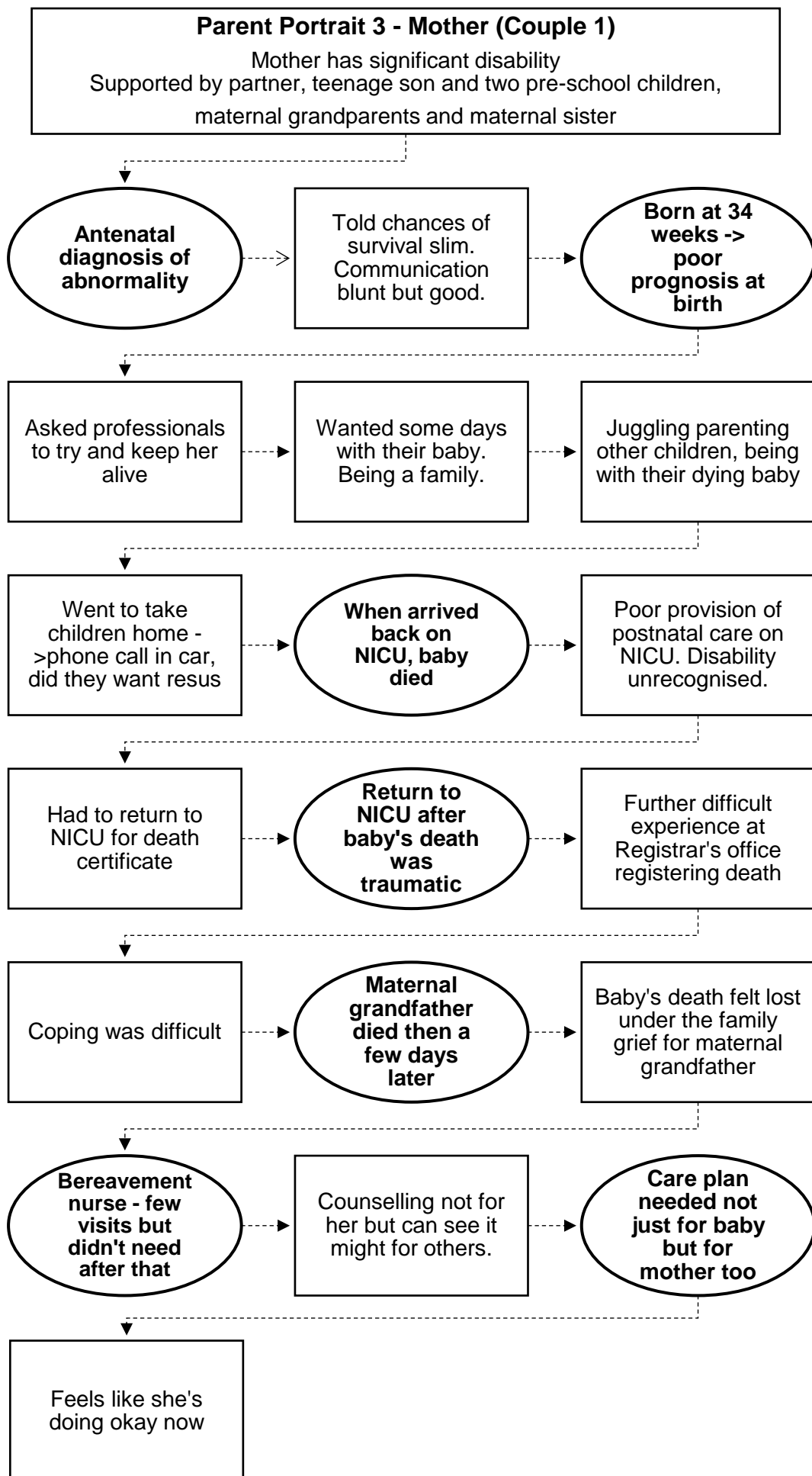
Although there are only five causes of death, they are different and represent the diversity of congenital abnormalities, complications of prematurity and acquired illnesses that neonates commonly die from. It is crucial to understand the complexity of disease progression, abnormality, disfigurement and complex life journey and death these babies have had. This understanding gives perspective to the events and emotions that participants experienced during their babies lives on NICU. It also provides a context for data analysis.

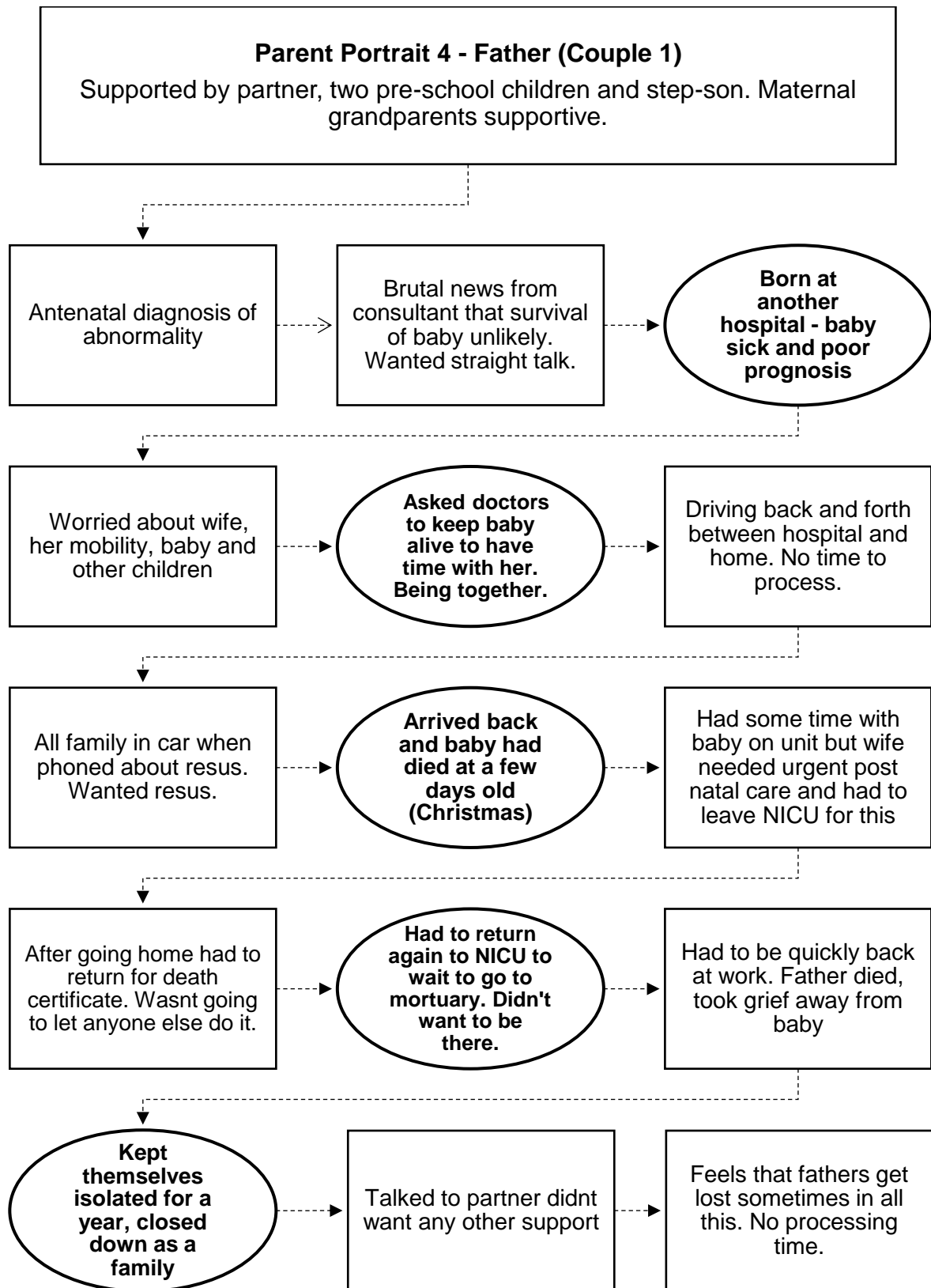
Parent portraits are included to assist readers to familiarise themselves with the individual characteristics of each parent and their unique journey through a visual

representation. Significant experiences are noted in boxes with more profound elements denoted by an oval.



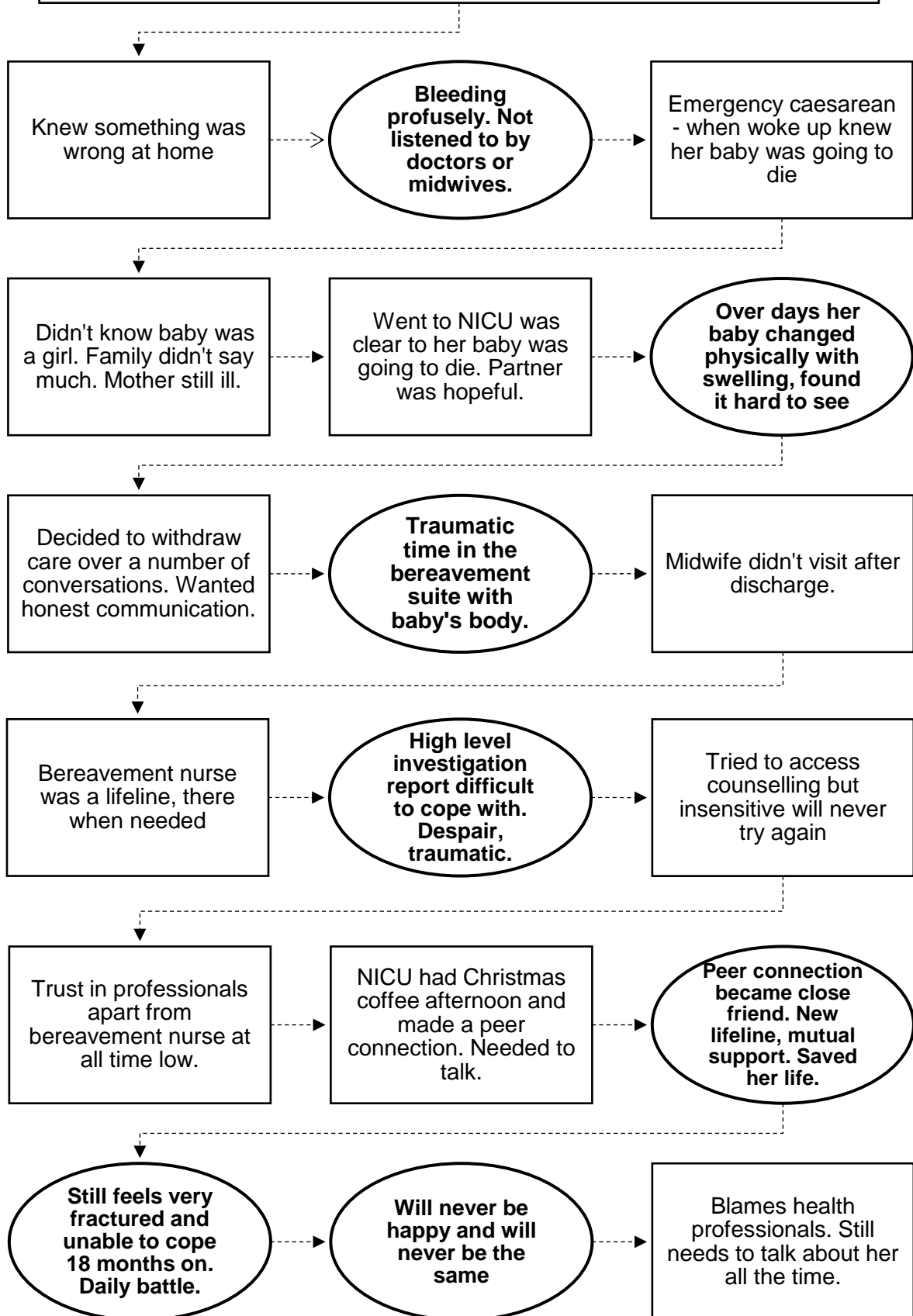




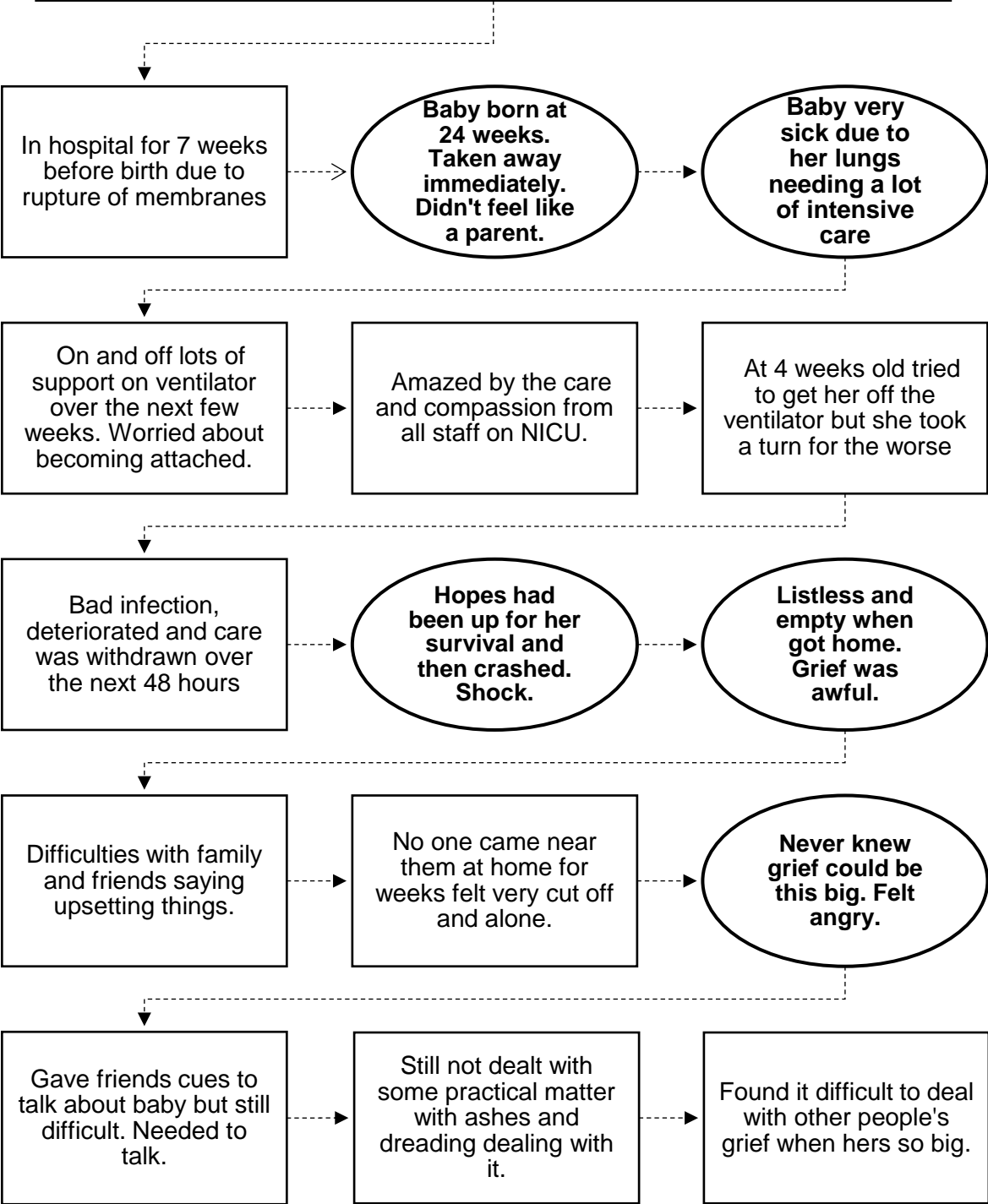


Parent Portrait 5 - Mother

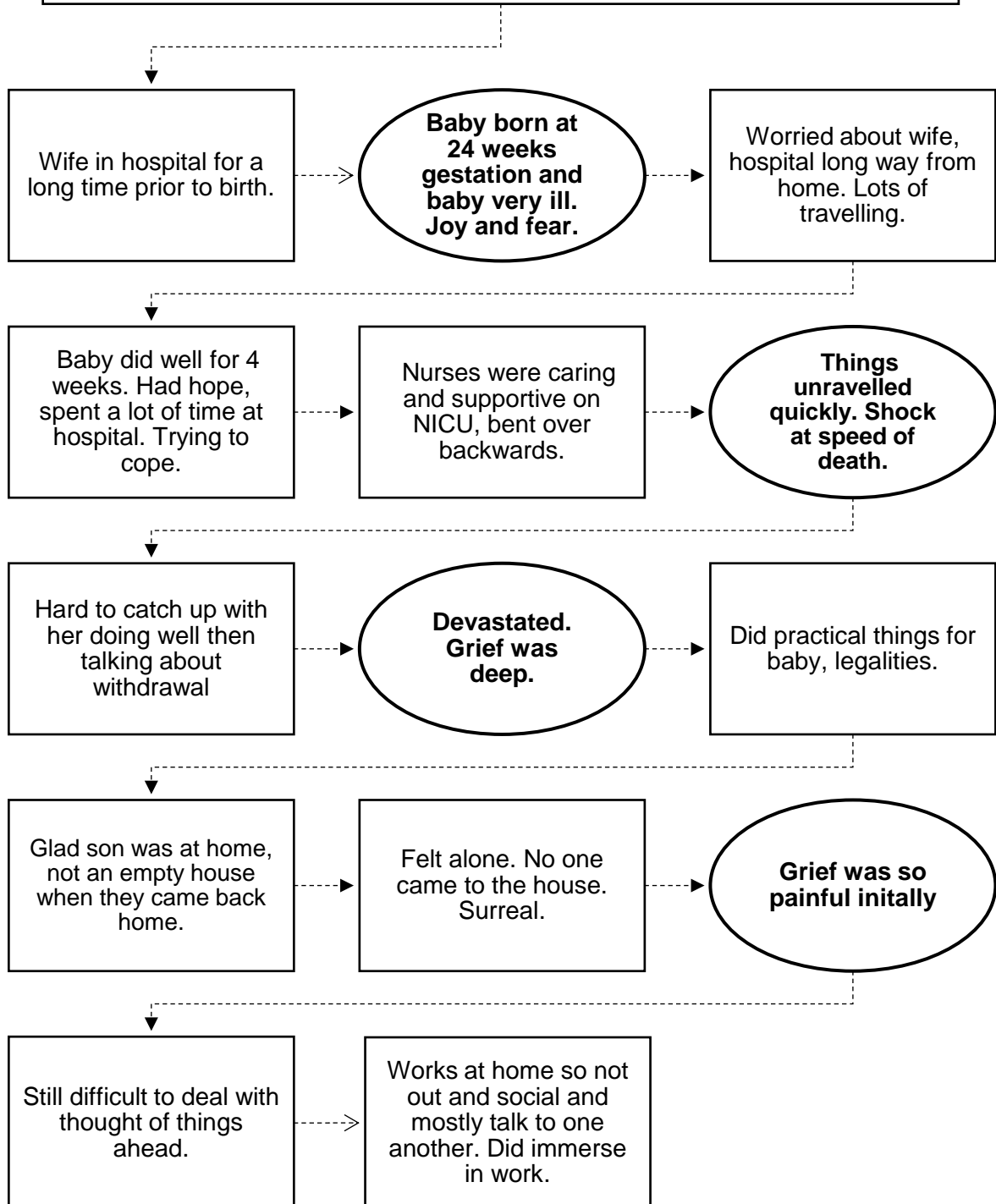
Supported by partner, and three other children



Parent Portrait 6 - Mother (Couple 2)
Supported by partner, both sets of grandparents and a toddler.



Parent Portrait 7 - Father (Couple 2)
Supported by partner, both sets of grandparents.
Teenage son and toddler.



6.3 Study findings overview

This section presents the four superordinate themes and subordinate themes (Figure 6.2). Participants will be referred to as ‘parents’ to reflect the compassion I felt for them when they shared their stories. Direct extracts from the original data will be used to judiciously illustrate the themes and bring the data to life.

Theme 1: The enormity of grief	Uncertainty
	Realisation their baby was dying
	Living through the event
	Life without their baby
	Hopes and desires
Theme 2: Being Isolated	Alone and isolated
	Isolated from social groups
Theme 3: Trying to Survive	Wanting their baby to be known
	Talking with purpose
	Family, friend and peer support
	Professional support
Theme 4: Routes to an improved future	Communicating clearly and with care
	Reframing the NICU experience
	Mapping appropriate support

Figure 6.2 Superordinate and subordinate themes

Reflection Note 6.1: parental identity and data extracts

As I wrote this chapter and the emotive content emerged, I did not feel comfortable continuing to refer to parents as the participants. To do so, seemed to diminish their role as the parent to their baby and appeared to reinforce some of their experiences of being disenfranchised in their grief. Referring to the parents by their role of mother, father or parent felt more in line with who they were as individuals and is more respectful of their position.

There are a small number of instances where quotations have been omitted. I made this decision for two connected reasons: first, the content of those narrative moments were just too intimate to share in a published thesis and second, I have done this to preserve the dignity and most intimate experiences of the parents. The openness of the parents meant that they did not withhold some particularly raw emotions and experiences, many elements of which I have conveyed and shared in data extracts. The few narratives that have been omitted have not altered the coherence of the findings or diminished the importance of the accounts presented.

6.4 Theme 1: The enormity of grief

The enormity of grief emerged as a superordinate theme and was a dominant feature across parent accounts. Whether the death of a baby was unexpected with limited preparation or an expected end to a palliative care situation, the enormity of the bereavement event and life afterwards was beyond the imaginable expectations of the parents.

Reflection Point 6.2: visualising the enormity of grief

As each parent explained the vastness of their grief experiences, I pictured a planetary 'black hole'. This entity appeared so enormous that it would be difficult to measure, they were powerless to control it or escape it and it seemed to feel hopeless to them. Visualising a black hole with a vortex that was dark and frightening helped me to understand the powerlessness that parents were describing.

Parents described being shocked by the intrusion of grief into every aspect of their waking life and how it also invaded their rest. Parents found their grief overwhelming and unmanageable, intensified by physical symptoms including insomnia, alopecia, sleep disruptions such as nightmares, appetite changes and being unable to eat, fine hand tremor and for mothers, post-pregnancy complications. For many parents, their narratives focused on their feelings, emotions, psychological distress and the overwhelming size of the experience. The following extracts highlight the impact of the grief:

"I don't know if you can see but I completely lost all my hair. I lost all my hair and it's just starting to grow back and I mean, it was completely bald. Just sheer stress obviously." **Parent 5, Mother**

"It's been terrible. Grieving, it's a huge thing in its own right. It's still ongoing two years later." **Parent 2, Mother**

"It's like you can't get over one because there's that many little bits to it, it's too big, it's too big. And I feel at this moment in time, I'm never going to be able... not resolve things, that's not the right word but I'm never going to be able to fully put a lid on it. It's too big, it's like one of them, we all hear it now and

again, one of them life-changing events in your life that do, completely and utterly, change everything you know as normal.” Parent 5, Mother

“I can remember thinking, I cannot be alive if my baby’s not. I remember I just refused to eat at first, thinking if she can’t eat, I don’t eat.” Parent 5, Mother

Parents did not know what to expect and described the grief as the most difficult experience in their lives. The enormity of their loss not only related to the immediate period around the death but unimaginable reality of living without their baby. Parents described acutely intense emotions in the first few weeks after their baby’s death, including being disconnected from daily life, family and friends. The following extracts summarise parents’ perceptions of their grief:

“It wasn’t easy to grieve for her.” Parent 3, Mother

“I never knew that daily life could be so affected by something like that, for me anyway... It feels like you have nothing to hope for again.” Parent 6, Mother

“I don’t feel it could have been any more tragic.” Parent 5, Mother

One couple described that they were over the worst of the experience, but most parents could not see an end point to the experience. The two parents who felt that life was getting easier were the most recently bereaved, however they still described a vast, unexpected and hugely painful grief experience. The ongoing intensity of the grief experience was overwhelming to a number of parents and the flow of grief pangs were painful and sometimes unrelenting, dependant on outside factors in their current lives, as highlighted in the following accounts:

“ We’re only nine months on and there are still things that we haven’t done, stuff that we haven’t broached, dealt with her ashes yet, but they’re odd things, the rest of life is back to normal, really.” Parent 6, Mother

“Grief isn’t going to go away. You can go right back to the day he died, right back to it.” Parent 2, Mother

The enormity of grief was multifaceted and interlinked with the five subordinate themes of ‘uncertainty’, ‘realisation’, ‘living through the event’, ‘life without their baby’ and ‘hopes and desires’, which are now described.

6.4.1 Uncertainty

Parents described either moments of or ongoing uncertainty over the facts and events that led to their baby’s death. Parents described constantly going around in circles, as they tried to comprehend what had happened to their baby; this added to the enormity of their grief. Uncertainty over prognosis, outcome and the issue of resuscitation added to parents’ disbelief about the events that happened to their baby and themselves. However, some parents reflected that in the middle of this uncertainty, somehow, they knew their baby would not survive, highlighted in the following account:

“Yeah, she was doing really well, she did really well right up until 36-48 hours up until she died, when she got an infection...It doesn’t feel surprising to me now, I think I always knew that she wasn’t going to make it, even though she did really well.” **Parent 6, Mother**

The babies died from a range of problems most of which were rare events, diseases, conditions or abnormalities (Figure 6.1). Consequently, most parents had been unaware of their baby’s condition prior to being pregnant or having their baby. One couple with an antenatal diagnosis of abnormality had received foetal counselling and accessed information to gain some understanding of the condition. However, all parents described struggling to internalise their baby’s diagnosis and the uncertainty of their baby’s prognosis. Many parents were left with unanswered questions after the death, either about diagnosis or care and treatment activities. The following extract illustrates one parent’s lack of understanding at the time of their baby’s death and ongoing uncertainty:

“I didn’t come round (from the anaesthetic) till half past seven and then I knew instantly that there was something wrong because it doesn’t take that long. And so I asked and they didn’t really tell me anything straight away, cause I was very poorly myself. It was about 11 o’clock that night when they came

round and said he was in neonatal, there had been a massive internal bleed, yeah, I don't know how to describe it." **Parent 1, Mother**

Parents' descriptions about the reason they thought their baby died revealed that for some they were still uncertain about the exact nature of their baby's problem. In line with national guidance, parents were offered a meeting with their baby's lead consultant approximately six weeks after the death of their baby to address any outstanding questions or uncertainties (TfSL, 2017). Parents described the reasons the meeting with the consultant were because they wanted answers to on-going uncertainties such as results from investigations that might help with a diagnosis and navigating their grief. In contrast, not meeting the consultant included perceiving the meeting had no clear purpose, poor timing (too soon after the event), inconvenient time or location of the meeting particularly if the meeting was on the neonatal unit. Some parents described an apathy towards the meeting, as it would not change the outcome that their baby had died. Other parents appeared resigned to not having complete answers to the events surrounding their baby's death. One parent, who felt her baby's death was a result of negligence, was deeply affected by the lack of answers and ongoing uncertainty about events. The following extracts illustrate parents' contrasting perceptions of meeting the consultant to discuss their baby's death:

"I haven't completely ruled it out (meeting the consultant). I think I knew that over the course of time, that I'd rationalise it myself and because I know that the decisions that they make, the area that they're working in is the very edge of what's possible." **Parent 6, Mother**

"I think that's why I say, me personally I find it very...I can't heal, I can't heal until I've got answers, I can't. It does make the healing process...., it's just horrific." **Parent 5, Mother**

Parents used the interview as an opportunity to reflect on their overwhelming uncertainty about the prognosis of their baby and difficulty understanding the information and discussions with health professionals. Some parents described their devastation about being asked about withdrawal of treatment, disbelieving that this would be a consideration. Parents perceived events would take their course and

therefore there would always be hope that their baby would survive. Parental uncertainty about the prognosis resulted in them asking health professionals to continue care, for example:

“We asked them to keep her alive, not withdraw care, didn’t we? I don’t think we understood at the time.” **Parent 3, Mother**

Lack of clear communication was perceived as a barrier to parents’ understanding about changes in their baby’s condition. In some circumstances, understanding about imminent death was delayed. Staff resourcing and availability of the right person to talk to the family appeared to have an impact on information being communicated on the day of death. Parents were left with hope that moved to devastation and back as they processed the possibilities, uncertain of what was to come. One couple while taking their other children home, and unaware their baby was near death, received a telephone call that their baby was being resuscitated and to return to the unit urgently. This lack of information about their baby dying imminently led to a traumatic cascade of events as described in this account:

“I think the thing was, the consultant wasn’t able to speak to you while we was there, he was tied up with something else. In the end, we got to the stage where it was like, we need to get the kids home.” **Parent 4, Father**

For this couple, this event was an irreversible situation. They were uncertain if taking their other children home it was the right decision but with the lack of further information decided to attend to the whole family’s needs. On return to the neonatal unit, resuscitation had ceased and they were taken to the bereavement suite, their minds catching up with the reality in a sub-optimum way. Consequently, they were not present to spend precious final moments because they were unaware their baby’s death was an immediate possibility. Parents perceived the lack of information in the hours before death and on-going uncertainty about their baby’s condition resulted in them missing an irreplaceable time with their baby. This couple have agonised over their decision to leave, which was based on a lack of information and uncertainty, as this extract reveals:

“But if we had been told beforehand, we probably would have been better able to put two and two together and understand what the real issues were.”

Parent 3, Mother

Some parents discussed their lack of understanding and uncertainty about what ‘do not resuscitate’ actually meant. Even after resuscitation discussions, parents revealed that they did not understand what resuscitation would realistically achieve, therefore never perceived it would be considered. Parents described resuscitation conversations happened either urgently at the moment of a baby rapidly deteriorating or very close to anticipated collapse. Despite the urgency, they were being asked to make a decision about resuscitation. Parents’ accounts revealed they based their decision on the immediacy of wanting to give their baby a chance at recovery, rather than an understanding that resuscitation would not manage the underlying problems. Some parents described not feeling in control about resuscitation decisions. The following accounts highlight parents’ uncertainties about the purpose of resuscitation:

“They said, I don’t think she’s going to last the night, do you want us to resuscitate? My gut reaction was yeah, of course I want you to resuscitate...I was thinking, they just resuscitate her and she’s alive again. Which maybe he should have said to me, it probably won’t work. Instead of me saying, you must resuscitate her and me thinking, they just resuscitate her and she’s alive again.” **Parent 3, Mother**

“But I didn’t understand then. I understand afterwards. It was kind of a no-brainer for me, you resuscitate her and then she’s back alive again, not understanding that it was her lungs that were failing, that were gonna kill her.”

Parent 4, Father

“You know you’re at the mercy of someone else deciding whether or not to resuscitate a baby like that. I think I didn’t want to be, I wanted to be a bit more in control, if you know what I mean?” **Parent 6, Mother**

In summary, uncertainty began at the time of diagnosis and the events that led to their baby’s death. Feelings of uncertainty developed as the grieving process continued and parents persisted in questioning the facts of their baby’s death, with

unceasing thoughts about ‘what-if’ and ‘maybes’. The uncertainty and disbelief that this painful event had actually happened appeared to permeate parents very being.

6.4.2 Realisation their baby was dying

Parents’ accounts revealed that there came a point where they realised that their baby was going to die. The timing of this realisation was often different to that of their partner, and therefore, an individual experience. For some parents this realisation came to being during in-depth discussion with a health professional about resuscitation as discussed in the previous section. Other parents described a series of smaller realisations that ultimately resulted in them comprehending the reality that death was imminent and unpreventable. For some, this realisation was late and close to the actual time of death or withdrawal of care. For others, the rapid progression from birth to death resulted in parents having little opportunity to process the birth event, before having to comprehend their baby’s imminent death. Most parents did not experience the joy of birth, for example:

“I woke up hearing ‘you need to go to intensive care, the baby is seriously ill’. I saw her, and I knew she was going to die, I knew instantly. I didn’t know I had a girl, but I knew she was going to die.” **Parent 5, Mother**

However, most parents described a specific conversation or a number of conversations with health professionals that led them to the final realisation that their baby would die. Some parents described clear, honest and straightforward ways health professionals communicated the prognosis of their baby and the inevitability of the situation. Some parents described a need for concrete examples as to why their baby would not survive such why blood results were incompatible with life, to help them understand the irreversibility of their baby’s condition. Examples of parents’ accounts of knowing their baby would die include:

“They did tell us, they kept saying that there wasn’t much hope.” **Parent 3, Mother**

“We were well prepared for it beforehand, weren’t we?” **Parent 4, Father**

“And it was in the morning that they started talking more about letting her go basically. And that’s what we decided to do, well we didn’t really decide...”

Parent 6, Mother

“He was really very, very honest and said, we don’t know how she’s still alive, she is to the point where she is not alive, she is breathing on a machine. He had given us for the first time, given us figures, I can’t remember the exact figures, it was something like her pH. If anyone has got levels under 4 point something, they’re basically dead and hers...” **Parent 5, Mother**

Some parents’ accounts revealed that the reality of their baby’s death was gleaned from what health care professionals did not say. Interactions appeared to have unspoken elements and through non-verbal cues. One mother described clearly the cues of omission, when health care professionals reported positive aspects of their baby but as time passed this stopped. This change was profound and was the moment that she realised there was no hope that her baby would survive, as described in this extract:

“We started to realise he wouldn’t survive when they weren’t able to say anything positive about him. The nurse looked at him and I could see by her face. I wanted someone to say something hopeful but she couldn’t because she didn’t want to be dishonest.” **Parent 2, Mother**

Parents’ narratives appeared to suggest the difficulty health professionals face when conveying the complex information that their baby’s care and treatment would not be successful in a way that is both meaningful and sensitive. Parents described how they replayed these conversations during their grief journeys both in their minds and with partners, friends and family, in an attempt to make sense of how the events unfolded. For some parents, this replaying of the conversation after the event continued to help them understand that their baby could not have survived under any circumstances. Some parents continue to reflect on these conversations, for example:

“It doesn’t feel surprising to me now, I think I always knew that she wasn’t going to make it, even though she did really well.” **Parent 6, Mother**

For some parents, the realisation that their baby was dying came from observing the physical changes as their baby deteriorated, for example watching for changes in vital signs on monitoring equipment or a change in the colour of their baby's skin. When monitoring equipment did not indicate an improvement in their baby's condition, parents began to understand the futility of the situation. Parents' accounts revealed the distress caused by witnessing their baby undergo relentless interventions that were needed to keep them alive, as highlighted in the following account:

"We knew what our last decision would have to be and there was no point keeping him in the NICU for our benefit, because it was just torturing him really." **Parent 1, Mother**

Parents' realisation that their baby was going to die no matter what treatment could be offered, was a painful process and not one isolated moment. The process of assimilating information and understanding that their baby was going to die often came together with a final, jarring realisation either arising out of a communication episode with clinicians and nurses or from spending time watching their baby deteriorate. Parents spoke spontaneously of their individual realisation that their baby was going to die without prompts or questions, and it was a profound and final moment. Processing the impending death of their baby appeared to have been part of most parents' grief work.

Reflection Point 6.3: parents' move to recount realisation

The narrative description for realisation was not prompted nor did it arise as a result of a question. Parents worked through their experiences of approaching end of life and wanted to share how understanding of the situation either 'hit them' or began to 'sink in'. I waited and listened as they worked through their thoughts and speaking about this realisation was emotive for most parents.

6.4.3 Living through the event

The experience of living through the death of their baby was prominent in all the parents' narratives. 'Living through the event' can be described as the period of end of life (for some babies this was a two or three days), the actual death of their baby

and the next few days if the family remained at the hospital. In NICU, best practice is to allow parents time with their deceased baby and not to rush this phase of being together or remove the baby to the mortuary quickly (Together for Short Lives, 2017). In these situations, some parents will not have held their baby before because they have been too unwell to be moved or if they have held their baby, those opportunities will have been limited. Therefore, this is precious time to hold, love, have the opportunity to dress, bathe and bond with their baby, creating precious memories. NICU bereavement areas or suites normally have access to a 'cold cot' in which the baby can be placed into for periods of time to stop the normal decomposition processes of a dead body. This strategy facilitates a longer length of time that parents can stay with their baby. When parents discussed the event of their baby's death, they referred to end of life, dying and after death on the NICU, for example:

"When we were still in the meeting with the doctor, I remember getting really upset and saying, you know, you're telling me my baby, you're telling us our baby is dying and we've never done anything more than hold her hand or stroke her foot. I remember the doctor then saying to the nurse, right, when you go back, lift the lid off for him, let him hold the baby and he did, he got in there." **Parent 5, Mother**

For one couple, they had known their baby had significant abnormalities and had not expected their baby to survive beyond the birth. Therefore, the few days their baby was in intensive care felt like a bonus and they cherished those moments, even though it was also an emotional experience:

"We were grateful she was born alive because we had some days with her." **Parent 3, Mother**

Some parents revealed that the number of health professionals involved in their baby's palliative and end of life care was difficult, as they perceived they had to repeat information about the pregnancy, labour and baby's history several times. Health professionals did not appear to consider the emotional burden of having to repeat this information. Parents' perceived that this was a history or clinical information gathering for health professionals with little understanding of how hard, emotive and upsetting this was, for example:

“It’s amazing how many medical professionals that you see, you must have seen well over one hundred medical professionals in your time from first going into hospital till leaving. And you often have to explain what has been going on, time and time again.” **Parent 7, Father**

For most parents, the end of their baby’s life was unbearable, emotionally and physically painful, incredibly difficult to witness and sometimes traumatic. Parents described the slow moving of time, how each change or deterioration in their baby’s condition brought a new rush of emotional pain, despair and helplessness. This phase of living through the event confirmed what the parents had already realised, that death was inevitable and irreversible. Parents revealed the lasting impact of this traumatic event; one parent described being distressed by the sight of blood, taking her back to her baby’s death. These examples are highlighted in the following accounts:

“So I still have periods, my own blood still traumatises me. I cannot bear the thought of seeing blood in that area purely because of what happened but I feel if I say to people, they look at me as if I’m odd. I’m like, ‘you don’t understand’. You do not understand that blood is to me like, it’s a thing that you need for life, you need blood in your body to live but to me its death ...red is evil, it’s evil.” **Parent 5, Mother**

“So we were there all afternoon just watching the numbers get worse and worse and you knew, didn’t you? At the time, you just wanted it to be over, didn’t you? You felt like it was dragging on.” **Parent 7, Father**

Across narratives, whether they had been informed of what to expect or not, parents feared the actual death, even if it was only minutes away. Information and knowing what to expect may have prepared parents but this did not reduce dreading the finality of their baby’s death. Most parents had stayed close to their baby at the end of life, spending time watching, touching and just being with their baby regardless of whether care was withdrawn in a planned manner or whether their baby deteriorated to a natural death. One parent had a jarring reality that she did not truly know what

her baby looked like. Parents described what it was like to watch their baby die, for example:

“You felt like it was something you were going to have to do, you were going to have to watch them take all the tubes out and everything but I think with hindsight, you do need that time. To process, I think so and make sure that you haven’t not done anything.” **Parent 6, Mother**

“I never seen her eyes. I just don’t fully know what my baby looked like because when she was alive, she had that much tubes on her.” **Parent 5, Mother**

“And they leave you alone with her so you don’t actually know the minute that she’s drifted off but it’s at some point in that time that she’s gone and a bit later a doctor comes in just to sign them off and then....” **Parent 7, Mother**

The couple previously discussed, who had already missed precious end of life moments, described being removed from their baby in the bereavement suite so that the mother could receive post-natal care. She reflected on this care in the interview and felt angry about having to leave her baby, as highlighted in this account:

“I had no painkillers, no food. I had to go and queue up at maternity the day after she died for 2 ½ hours to get my postnatal check.” **Parent 3, Mother**

One mother was unable to describe the end of her baby’s life and she had made a purposeful decision never to discuss this; it was two years since the death of her baby. She perceived it would be too difficult and painful to think about her baby’s actual death. This same parent was able to say that having familiar nursing staff around was helpful at this time. Another mother also felt traumatised by the end of life period and found existing in those moments very frightening at the time. The following extracts illustrate these issues:

“I have really traumatic memories about the way in which my baby died. I had to block out a number of memories because it traumatised me. I still don’t think about these. It’s not just the fact that we’ve lost him but the awful memories

that we block out...It helped to have familiar nurses around.” **Parent 2, Mother**

“Out of everything, I remember this, and I am still embarrassed to say this but I remember feeling frightened of her [her baby]. I remember thinking, it’s like a horror film.” **Parent 5, Mother**

Reflection Point 6.4: deciding not to probe

When Parent 2 stated that she could not discuss the end of life event for her baby and she explained that the memories were too traumatic, I respected her need to separate herself from those memories and did not probe that element. I told her that this was okay and to tell me only what she was comfortable thinking about.

Some parents shared their thoughts and feelings about being in a room with their deceased baby. In some instances, parents were in a dedicated bereavement suite, other parents were in a side room. Parents described this as a valuable opportunity to hold and cuddle their baby and for many parents for the first time as the following accounts highlight:

“It wasn’t feasible to hold her because of her condition. Afterwards we were able to hold her.” **Parent 4, Father**

“That was all I was bothered about at the time. I said, will I get to hold him?” **Parent 1, Mother**

“I remember the doctor saying to me, ‘do want me to get her out so you can hold her?’ And I remember saying, ‘no, she’s going to die today, so I will hold her when she’s got no tubes’ and I kept on saying, ‘she has to die with me, she cannot die in here with ‘yous’, she has to die with me, I am her mum.’ And that’s what we did, that’s what happened.” **Parent 5, Mother**

All parents valued privacy during the whole end of life period. Providing a private space appeared to facilitate the expression of emotions in whatever way parents wished. Loving words could be uttered without being overheard, babies were bathed, dressed, held, cuddled, photographed, and videoed and memories were made. This

time was precious and yet short and parents described that they were not rushed and could have as much time with their baby after death as they wished, for example:

“The bereavement room was nice. It was me, my partner, our son and our baby. We were able to hold her.” **Parent 3, Mother**

“The neonatal team had done all his memory box and everything; they really looked after me that way, the lock of his hair and things like that. Yeah, it expands every day, his memory box.” **Parent 1, Mother**

Some parents felt ill prepared for how their baby would look at the time of death and how their baby changed as the time of death passed. One parent described wishing she had been more prepared for how her baby would look and change in death, as the distressing signs of decomposition were unexpected.

“And she was very different then, wasn’t she? I mean, from a couple of days before, when we took those photos and she had her eyes open, looking at you and stuff.” **Parent 6, Mother**

“Like I said to you before, I asked about rigour mortis, no one told me that her hair would change colour and it did, her hair changed, it changed this mad colour during the death. I don’t know if this is normal but her eyes started to protrude, they started to bulge out and no one told me to expect that.” **Parent 5, Mother**

Reflection Point 6.5: distressing photographs

This mother showed me pictures of her baby at birth and her baby after death. The distressing features of her baby were unusual and upsetting. Although I knew it was probably due to gross oedema prior to death and it would have been difficult for staff to predict some elements of the changes that her baby underwent. I did not explain the change in appearance but focused on listening to her narrative. She found these memories and pictures traumatising and she said she never really looked at the pictures: she found it too hard.

No parent described the same experience or emotional response. One couple interviewed at the same time, described how their emotional experiences differed,

although at times they felt they shared similar emotions and thoughts as their accounts highlight:

"We kind of are both very different in our outlook, really. I was always more positive and you were a little bit more cautious, shall we say" **Parent 6, Mother**

"It's just the way that we deal with it, these things." **Parent 7, Father**

Reflection Point 6.6: couples' compassion and respect for one another

Observing this couple during the interview, there appeared to be a respect for each other's experiences, taking time to listen to one another and allow each other to correct facts. Further, I also witnessed in the couple interviews, gestures of expressing compassion and empathy towards one another's experiences. These gestures were extended through touch, non-verbal motions such as facial expressions and verbal assent, intended to offer comfort and support.

Across all parents' accounts, living through the death of their baby was a deeply sad event. Most parents were overcome with emotion as they shared their narrative, particularly when describing the events of their baby's death, however each parent appeared to have a need to disclose exactly what it had been like and how it felt; the narrative was graphic at times. Parents were open and honest about these private and personal experiences and some stated that it was the first time they had spoken to someone about the actual journey of end of life and that they were glad they had been able to finally talk about it.

Reflection Point 6.7: researcher emotion hearing end of life accounts

Listening to parents describe the end of life was an emotional experience. Although I have been a nurse caring for babies and their parents at this stage many times, I felt the emotions of parents' experiences of end of life acutely. Their accounts of the events were so raw that hearing it from their perspective was profound and different to witnessing the death of a baby in real time. There were some interviews where I had to control and compartmentalise my natural emotion until the interview was finished; I was then able to release the sadness that I felt. The emotional impact of these end of life accounts has continued into analysis, interpretation, writing and proof reading.

This subordinate theme and each of the parent's narrative about the end of life event conveyed a multi-faceted experience of the practicalities of end of life, difficulties of

seeing their baby go through this experience, a range of emotions and precious memory making.

6.4.4 Life without their baby

Parents spent significant time in the interview describing their life, individual moments and difficulties in the time after their baby's death. As this was an unstructured interview, parents steered the direction of narrative with little prompting or probing. As previously discussed in Chapter 5.2.3.2, narratives were not linear and therefore when parents talked about events at end of life, they often moved to revealing their feelings contemporarily. Parents appeared as motivated to talk about their experience of life without their baby as they were about their baby's life. For all parents, life without their baby has been painful.

The first days and weeks after the baby's death were profoundly difficult across all narratives. Some parents recalled feeling fractured, with disordered thinking and being unable to function on a basic level. They described time passing slowly and fast at the same time and at different junctures, sometimes losing days at a time without much memory. Many parents had to care for their other children, which they described as an additional challenge at an already difficult time. Parents relied on family to assist them in managing every day events in those first weeks. The following extracts highlight the difficulties of those first days.

"You emerge from that clinical world, where you've, day in day out, your life is ruled by the hospital and you're hoping for this great outcome and then suddenly.... "

"It feels like you have nothing to hope for again." **Parents 7 & 6**

I'd take my little boy to school and be on the bus home and I was like that, 'I don't know where I live, what bus stop do I get off at?'" **Parent 5, Mother**

“When we came home, we had our son here running around and he knew nothing about what had gone on and it was like ‘bath time’ just you know, it was just a big reality check at the end of the day, wasn’t it?” **Parent 7, Father**

Reflection Point 6.8: differing and chaotic narrative structures

One parent appeared to have chaotic thought patterns with the whole narrative appearing muddled, moving back and forth continually between events and timeframes. However, this narrative, even though it was structured differently, was rich in valuable data.

Parents did not seem to have any preconceptions about what the beginning of their grief journey would be like, what to expect and how to live with the reality of their baby’s absence. Early grief arrived with limited or no preparation as events leading to death were often described as shocking and unexpected. Parents revealed being distressed by changes in their cognition, short and long-term recall was affected, as was the ability to mentally organise through to practical organisation, for example:

“I think we went through a stage where I think were you (partner) were probably more stable I am. I was in bits, wasn’t I, for a couple of weeks and then sort of got out of it a little bit quicker. Where for you, probably you were more measured, but it’s taken longer.” **Parent 7, Father**

“It’s awful, awful and I would be like, ‘what’s my name, what am I doing, where do I live?’” **Parent 5, Mother**

Parents described it being difficult to be at home without their baby as most had expected to be coming home with their baby. All parents had prepared for their new arrival; therefore, returning home without their baby meant facing all the hopeful preparations, gifts and reminders of what they had lost. Returning home was both a comfort and a source of distress for all parents. As time passed, being at home without their baby made parents feel more bereft, outlined in the following accounts:

“And that’s it, they shut the door and you go home and you sit at home and you’re like...oh, it’s awful. It’s awful, it’s horrid, you don’t know what you’re supposed to do.” **Parent 5, Mother**

“So you just felt like everything was a battle after she died and also I felt when we first got home, because I’d been so torn between home and hospital, it was sort of a weird feeling.” **Parent 6, Mother**

“Your mum was here as well, wasn’t she and if we didn’t have her here we would have just come back to an empty house, that would have been even harder.” **Parent 7, Father**

Some parents described returning to the NICU for a death certificate added to their distress. Those who described this negative experience did so passionately with a wish that it had not happened and should not happen to others. Parents highlighted that they did not want to return to the place their baby had died in this early grief period where they might meet other parents they knew, hear babies crying, hear machines and alarms or meet familiar staff. Returning to the NICU for review appointments was a significantly difficult hurdle for parents because it meant revisiting the unit and experiences of sights, sounds and smells that they associated with the life and death of their baby as the following accounts highlight:

“It would have been nice not to have to go back to neonatal to get the death certificate. Then we had to go to two registry offices. By that stage, we were sort of jaded and frustrated and hassled and bothered.” **Parent 4, Father**

“So the review had to happen on NICU.” **Parent 2, Mother**

For many parents, there was a particular time in the early weeks/months of their grief that their life unravelled and a crisis point was reached. Some parents described mental and physical dysfunction such as lethargy, inability to concentrate, altered cognition, sleep disruption, alopecia, loss of appetite, memory problems, anxiety and overwhelming distress. These crisis symptoms were evident to themselves, partners and family members. Parents described a range of way to manage these reactions such as hiding away, seeing their GP or leaning on confidantes. In some cases, a partner or family member had intervened and sought help on the parent’s behalf including searching the internet for information about support groups. Help did not

always come quickly or in the right format for parents at this time of crisis. The following extracts highlight parents' crisis moments:

"I remember it was a week and not one person had bought me a condolence card or a congratulations card and I just lost the plot and I just screamed and I was saying and I remember they were saying, 'I don't know what we're supposed to do'. And I remember looking thinking, no one cares, I know they did but I didn't have nothing." **Parent 5, Mother**

"I got more angry at people, quite a few weeks afterwards, like little things that people would..., it would make me angrier than before." **Parent 6, Mother**

"My partner got in contact with the bereavement staff. I just wasn't functioning." **Parent 2, Mother**

Some parents talked about an adaptation that gradually occurred where they continued to grieve but became accustomed to the situation of their baby not being with them. Those parents described adjusting to the loss but not feeling any less pain, they also described peaks in their grief in certain situations or certain triggers were likely to cause this. The following extract summarises parents' perceptions of their slow adaptation to grief:

"We had 9 months to prepare for the circumstances to do with our baby's treatment. We had to get used to it [the grief] or anticipate how it would be." **Parent 4, Father**

"We got through that first year. But this year we started sort of taking an interest in things, haven't we?" **Parent 4, Father**

One parent was still experiencing a significantly painful, daily grief and this parent could not sense there would be an easing in her grief over time. This parent identified that her situation was out of the ordinary for even the unusual circumstances of a baby dying. Professionals' decision-making and communication continued to have an intruding effect on her daily life, as did the traumatic nature of the baby's birth and

death. This parent described requiring considerable ongoing support from professionals, peers, friends and family at 18 months, for example:

I became so bitter and that was the circumstances rather than the death, does that make sense? It floored me, it has changed me forever, I will never trust a professional again, ever.” **Parent 5, Mother**

“It’s like one of them life-changing events in life that do, completely and utterly, change everything you know as normal.” **Parent 5, Mother**

“You get that wrapped up on the negative that you can’t focus on the positive because in your eyes there is never a positive again. You become engrossed in negativity and bitterness. It eats you, it eats away at you, it’s horrendous.”

Parent 5, Mother

All parents articulated how life had changed by the experience of the death of their baby. Parents felt they were a different person, with a different personality and outlook on life. They described being certain that their life would never be the same again nor did they feel they could reach the potential of happiness that it could have been if their baby was still alive, for example:

“You know, it just, it blows you apart, I’ve never been the same person, I look the same and I sound the same and you know but inside, you just walk round, and you’re lost, you are completely lost.” **Parent 5, Mother**

“Because of many other problems in our personal life, it’s difficult to take a positive step forward.” **Parent 2, Mother**

Summarising this subordinate theme of ‘life without their baby’, it is difficult to feel a sense of completion, because I know that these narratives are only a part of what life will be like for these families without their baby; it is a prospective journey for them, as well as the retrospective view narrated in this thesis. However, this subordinate theme reveals the multi-faceted nature of parents’ diverse experiences of living life without a vital family member and how that intrudes on functionality, emotions and practicality.

6.4.5 Hopes and desires

The subordinate theme of parents' hopes and desires emerged in the collective parental narrative. There was a clear sense of parents yearning for better times in their lives and for improved psychological well-being. This was described as a desire to keep their deceased baby close in their minds, in their dialogue and family. However, as one parent described, it could be difficult to hope for anything better and it was easy to be despondent about the future. Nevertheless, this parent was able to articulate a desire for an improvement of care and support services for future parents suggesting she was moving in a forward trajectory. Most parents found hope and a degree of contentment in being able to remember their baby and undertake some normal life activities again as the following extract highlights:

"We do a lot of things based around him, like for his birthday we went away and we always visit the cemetery...And it's a really nice place for him to be. We go just when we fancy, I mean, I go more often because I have days off work in the week...It really helps." **Parent 2, Mother.**

"It's the same like this now, when you're talking about, this will thingy me for about four or five days, I will be crying for days and days and days but I know it needs doing and things like this are important. If people don't say it, you will never know, will you, how people feel?" **Parent 5, Mother**

Across parents' accounts was a desire to remember their baby's short life and the experience, however painful. Parents described the hope that their baby would never be forgotten by their family; they were convinced that they themselves would hold their baby's memories close and prevalent. Parents described a need for their babies to have an on-going presence in their daily lives and to remain a current part of their family. Most parents perceived a degree of negativity from friends, family and co-workers about their desire to keep their baby present in their lives. Parents gave examples where people had suggested that it wasn't healthy to keep talking about, remembering and considering their baby as part of their family, often being advised to 'move on' from and 'let go' of their deceased baby. The following accounts highlight these experiences:

“My friends... they don’t know what to say to you. I don’t know how to explain it, they’re always there for you and they’ll recognise that he is my son and he always will be, but they don’t want to talk about him.” **Parent 2, Mother**

“I think everyone’s moved on now and it doesn’t come up in conversation hardly at all now, does it? It’s on the forefront of our minds the whole time.”
Parent 7, Father

Some parents’ desires and hopes focused on having more children. They did not wish to replace their deceased baby but the desire for another baby was strong. One of the parents had already had another baby, one parent was pregnant, and one mother had experienced a miscarriage since the death of her baby. Some parents were trying to conceive, and another parent was unable to have more children.

“His new brother is the one positive thing since losing our first baby.” **Parent 2, Mother**

“And recently, two weeks ago, I found out that I was pregnant again. You kind of don’t expect to be excited, you prepare yourself for the worst.” **Parent 1, Mother**

‘Moving on’ and ‘letting go’ was upsetting for parents and they perceived this trivialised their experiences and the meaning of their baby’s life. However, parents described that the support from other bereaved parents reinforced the normality of their hope and desire to keep their baby close and part of their family whilst beginning to enjoy aspects of life again. They revealed a fierce and instinctive need to keep their baby close to them as they navigated life ahead. Some parents had moments of hope about the future and believed that life could improve for them.

6.5 Theme 2: Isolation

Isolation emerged as a superordinate theme as parents described their experiences both during end of life and life after the death of their baby. Isolation was a dominant feature of parents’ narratives of their life after their baby’s death, and yet the way in which isolation was manifested was unexpected and in many ways bewildering for

them. Across parents' narratives were examples of unhelpful, insensitive, tactless and at times hurtful interactions with people close to them that they had expected support from and further heightened isolating feelings. In addition, parents revealed that they had experienced purposeful avoidance and exclusion by and from friends and/or friendship groups. These interactions reinforced how remote their situation was from their peers' daily lives and that seclusion was helpful to protect themselves both in the short or longer term. The following extract illustrates how removed from peers this mother felt:

"Friends can be sympathetic or empathetic, but they never understand."

Parent 2, Mother

Parents described the experience of being isolated from their peers, their families, their partners and social settings. Isolation appeared to impact on parents' emotional wellbeing. The two subordinate themes, 'alone and isolated' which represents parents' narratives of isolation on a personal level and 'isolated from social groups', reflecting parents' experience of feeling isolated from their friends, groups, communities and sometimes from their family are now described.

6.5.1 Alone and isolated

Parents' narratives often referred to a sense of isolation; feeling alone in their grief, feeling secluded and separated from real life and people who were previously prominent in their lives. This appeared to be a jarring, unexpected occurrence and all parents experienced it. Many people surrounded parents during their babies' short lives and some of this comfort and support continued until after the funeral. However, parents described a point at which everyone appeared to withdraw from them. A prominent feature across parents' accounts was the isolation that arose as a result of the loss of the relationships and support of health professionals. Parents had made significant connections with health professionals and they had not previously considered the sudden loss of their support network in the NICU. Many parents described nurses in particular going beyond their perceived duty in caring for their baby and developed a connection with their baby that many of their other family members had not. The sudden homecoming without their baby but also leaving the health professionals they had relied on, left a profound gap in their lives and added to their isolation as the following extracts highlight:

“They’re a different breed, these girls (nurses) are just a different breed. They were amazing.” **Parent 7, Father**

“The NICU staff, all of them were so helpful.” **Parent 6, Mother**

“There’s no gelling between the NICU and where you go next. There’s nothing.” **Parent 6. Mother**

A factor that appeared significant and added to parents’ isolation was the change in personal identity. Parents had spent the pregnancy seeing themselves as mothers and fathers to-be. The death of their baby left them with a crisis of identity, knowing they were a parent of their deceased baby, but now that their baby was gone, questioning whether they really were a parent. This crisis of identity left parents feeling isolated from their antenatal peers and friends. The parents who revealed this identity crisis had experiences of correcting professionals, family and friends about their parental role as the following mother highlighted:

“I am her mum.” **Parent 5, Mother**

Reflection Point 6.9: parental identity

When parents revealed their worry about parental identity, it was as though they thought it was a secret and there appeared to be a sense of shame. They seemed to expect a judgement from me but by using supportive non-verbal communication I just encouraged them to continue. When those parents stated that they had not shared this before, this confirmed their sense of trust in me. It was probably easier to disclose to someone independent than a loved one or friend.

This silence over the identity of being a mother or father reinforced their feelings of loneliness and overall built into a feeling of personal and emotional isolation. The following accounts highlight the sense of abandonment and arising remoteness.

“After a few weeks, everyone just disappears and you feel like, that’s it now, I’m on my own.” **Parent 1**

“I think it’s good that people acknowledge it. We also felt like we were dropped off the edge of the planet, didn’t we for a month or two, because I think everyone thought ‘oh, I’ll leave them alone or whatever’. Night after night, we were sat here, not speaking to anybody were we?” **Parent 7**

Some mothers described the isolation that came from wanting to talk about their baby but not finding willing listeners within family and friends. These mothers felt a sense of rejection that reinforced their loneliness. The notion of parents’ need to talk is explored in a subordinate them in Chapter 6.6.2. One parent described being geographically removed from her family and how isolating that was for her, for example:

I think what I personally find hard is, I don’t leave near my family. I know five miles is not a long way, but it is when you don’t drive. My sisters are working and everything. What I’ve found is that I’ve just isolated myself. **Parent 5, Mother**

All parents identified differing emotions between partners and each parent had a long-term partner or spouse. Two sets of couples were interviewed and they referred to their differences in emotions and grief journeys. However, they appeared to talk to one another about their feelings, as there was a desire to know how the other was feeling and a need to navigate the deep and painful emotions together. The three individual parents that were interviewed also referred to the differences in emotions and style of grieving between themselves and their partner, with two reporting that these differences isolated them from their partner. These parents described the difficulty they had talking to their partner, who either didn’t want to talk about it as much as them or there was a reluctance to add to the burden of grief by talking more, leading to a sense of loneliness and uncertainty. In the following accounts, the differences in emotions and arising isolation are highlighted:

“Well, my partner had work, so he could always go and there were these work people, work things who didn’t even know what had happened. I didn’t have that, so, just normal things like driving the car to Tesco’s and buying something was just the weirdest feeling, it was like I’d never done it before. Just things like that were quite odd.” **Parent 6, Mother**

“Actually, I speak to my mum more than my partner. My partner is stressed with work.” **Parent 2, Mother**

Reflection Point 6.10: couple and individual interviews

In the three individual parent interviews, only one perspective is represented as opposed to the couple interviews where parents collaborated in conveying the narrative. It was very different how a narrative unfolded with two people building on one another's experiences and perspectives. I gained wider insight into their baby's life and death and how a couple navigated these experiences alongside one another. I did not observe any conflict in the couple interviews. However, parents would, on occasion, correct a fact.

Some parents identified that their isolation came from an inertia that developed post-bereavement. Observing the world, friends, family and work colleagues still functioning and navigating life as normal when nothing was normal for them was distressing. It was hard for parents to witness life continuing in the same way and this experience heightened their disconnection with life, loved ones and society in general, for example:

“And then you emerge from that and you just look at the world around you and everybody is just going around doing their day to day.” **Parent 7, Father**

As parents described this personal experience of being isolated, it appeared that leaving the hospital and losing their parenthood was enforced on them. It had happened to them, without their consent, therefore the arising isolation, and the effect it had on their emotions felt forced upon them. Parents did not want to feel isolated over these issues but nevertheless, it was one of the many consequences of their baby's death. Parents who described this sense of being alone appeared to resent it, they did not want to feel so remote and perceived that no one knew what they were going through or how they felt, for example:

“The only person that I saw when I come home was the midwife because they had to have my stitches taken out and from then, I didn't really have any support apart from my family.” **Parent 1, Mother**

Listening to being alone and isolated from the parental lens revealed the lack of control they had in relation to the experiences happening to them. Parents did not feel any control to be able to reverse or avoid this experience. Some parents had noticed an improvement on this feeling over time and others hoped for a resolution as time progressed. Being alone and isolated links to but is different to the subsequent subordinate theme of 'social isolation'.

6.5.2 Isolated from social groups

The subordinate theme of being isolated from social groups differed in both experience and context to being alone and isolated. All parents' narratives had experiences about how they felt removed and isolated from their local communities, their friendships and acquaintances and on occasion from their families. Being isolated occurred across the whole trajectory of parents' journeys, from the point of knowing there was a problem in pregnancy in some cases, to the birth of their baby and then to life after the death of their baby. Parents described becoming isolated socially as a choice and sometimes against their will, for example:

"I hid away, I still do it 14 months on, I hide away from the world." **Parent 5, Mother**

Social isolation as a choice appeared to be a protective behaviour that parents adopted and used immediately after they knew their baby was ill. Parents were unable to share the joy of their baby's birth and therefore they avoided people except select family members. Some parents revealed that they did not let friends know their baby had been born, sometimes from choice but often because they were too upset and absorbed with the care, decisions and emotions surrounding their sick baby. Parents had allowed family to inform friends and wider social groups once their baby had died. It is reasonable to expect that close friends of the parents would want information of the birth and be concerned about not being able to get in touch with their expectant friend. However, for some this lack of contact did result in friends not attending the baby's funeral and dismissive statements about the gravity of the death of a child and its effect. For some parents they just felt angry with life and anyone around them, so being away from other people helped as the following extracts demonstrate:

“And hence why me and my friend are not friends, she never came to my baby’s funeral, she never came so I was like, done. Done. She didn’t come to my daughter’s funeral, so that was the end of that one.” **Parent 5, Mother**

“Oh, I completely blew my top because this bloke cut me up at the traffic lights or whatever and someone else from outside saying, ‘Oh, you’re really getting more angry about things than you would normally’. So you know, the whole world seemed really unhelpful for a while.” **Parent 6, Mother**

“We had a year of not feeling like giving very much, didn’t we? So last year, we didn’t do much of anything.” **Parent 4, Father**

“What I’ve found is that I’ve just isolated myself because I can’t deal with pregnant women. I do not go anywhere near newborn babies. If someone has a new born baby girl, that’s it, I cannot. I’ve lost so many friends, so many people I’ve always spoken to. I feel like I’ve got nothing in common.” **Parent 5, Mother**

Parents described some of the hurtful and tactless statements that were made to them including dismissive and insulting statements about the grief experience; being avoided by friends was equally hurtful. Parents spoke about avoiding friends from once hurtful comments had been made because this added pain to an already difficult grief journey. The following extracts summarise parental perceptions of these experiences:

“I’ve lost so many friends, so many people I’ve always spoken to. I feel like I’ve got nothing in common. And they don’t understand, so many people that I spoke to for years just ignored me because they just didn’t know what to say. They choose to pretend they don’t see you, they walk another way.” **Parent 5, Mother**

“And then there’s still things that happen, people don’t upset you deliberately, but things happen, and you think, oh well, I don’t think I want to be invited to a baby shower this year. But they don’t mean it.” **Parent 6, Mother**

“You get other people that we expect a bit more from and they pop round or something like that, but they won’t even mention, they just try to avoid the subject altogether.” **Parent 7, Father**

Navigating existing friendships proved to be inherently problematic. Parents expected to be surrounded by their close friends, but contact was sparse or did not occur at all. Parents actively sought comfort and a listening ear from friends and when this was absent, they felt further distress and it had a consolidating effect on their grief. Many parents felt let down by their friends and felt sure that they would not have acted in this way. Accounts of these isolating behaviours are highlighted here:

“I think everyone thought ‘oh, I’ll leave them alone or whatever’. Night after night, we were sat here, not speaking to anybody were we?” **Parent 7, Father**

“My friends were initially great but then they stopped talking about it. Then I stopped using them as a support.” **Parent 2, Mother**

“I think everyone’s moved on now and it doesn’t come up in conversation hardly at all now, does it?” **Parent 7, Father**

Some friendship experiences left a significant impact on several parents. They described friends’ avoidance behaviours but surprisingly, despite these encounters, some parents were able to be gracious about it. Nevertheless, in some cases, parents found these actions or inactions unforgiveable and friendships had dissolved as a result. The loss of most friendships, in one time period, left parents feeling secluded, rejected and untouchable. This element of social isolation was out of parental control and parents had no wish to repair damaged friendships. Many parents referred to the need for new friendships with people who had experienced similar circumstances rather than trying awkwardly to navigate damaged friendships. The following accounts illustrate parents’ experiences and arising needs:

“And then you get other people that we expect a bit more from and they pop round or something like that but they won’t even mention, they just try to avoid the subject altogether.” **Parent 6, Mother**

"My friend and I from NICU, we talk very openly. It wasn't just me and her, it was me her and my partner and her husband. We meet up at hers...it's like our time to dedicate to our girls because that's what we speak about. But I honesty and truthfully believe that because I met her last November obviously and I feel if I hadn't had her, I wouldn't like to think." **Parent 5, Mother**

"The only thing I've not liked about it is that people make it, by not mentioning it, or being odd about it, they make it your problem, it's your job then to mention it. And I don't think I've ever realised that before about dealing with someone who is bereaved, is that by bringing it up, you giving, it's such a relief for a bereaved person. Because I feel like I have to drop my baby's name into conversations as a little cue to people to say, 'it's okay to talk about her, I'm not going to melt if you mention her, or a baby or anything'. But it does, when people, the really hard work people, you're thinking; wait a minute, why am I making this easier for you?" **Parent 6, Mother**

Parents also related similar hurtful experiences with family members. This appeared to be unexpected and the insensitivity in discourse was cutting. These experiences affected the confiding relationships parents expected to have with their family. Being isolated from the family group, appeared to cause an increased level of emotional pain, for example:

"I think family is difficult, I mean we had a lot of help with our other child and everything but they're also the people who put their foot in it the most."

Parent 6, Mother

"There is still support from your family, but some of them don't like to talk about it." **Parent 1, Mother**

"My dad would come up with something like, 'you know, at first I was miffed.' That they weren't going to the funeral and he didn't get a chance to hold her and stuff like that so he was expressing to us, his dissatisfaction, whereas actually, we were quite, we had a bit more to worry about, didn't we?" **Parent 7, Father**

Most parents had other children and one of the trigger situations for isolation appeared to be the school playground. The thought of the unmanageable social situation of returning to the school playground to pick up their other children without their 'baby bump' and without a baby was a difficult hurdle. Mothers described that they imagined the questions that would come about where their baby was. Avoiding school and waiting in the car or arranging for others to assist helped. Parents purposefully withdrew in the early months to manage situations and keep any discourse about their baby's death within their control. One mother recounted conversations in the playground:

"It annoys me when people say, oh you're not yourself today. That bugs me and I just think bugger off and leave me alone. Parent 3, Mother

Parents were able to reveal that the social groups they had previously been a part of were often not a place of comfort and support after their baby's death. Parents experienced being part of these groups (family, friendships, communities) and yet they were alone and isolated. Most parents did not expect to regain their original social groups outside of family and felt that new social groups were a likely result.

6.6 Theme Three: Trying to survive

Trying to survive emerged as a superordinate theme from the collective parental narrative. Parents described experiences of difficulty coping and trying to survive each day. This superordinate theme is separated into four subordinate themes of: 'wanting their baby to be known', 'talking with a purpose', 'family, friend and peer support' and 'professional support'. The subordinate themes represented in this section will also reflect the different kinds of experiences parents had including positive, negative and neutral.

6.6.1 Wanting their baby to be known

Narratives across parents' accounts revealed an overwhelming need for their baby to be known by themselves and by others. This desire did not go away with the death of their baby, and if anything appeared to be heightened over time. The short duration of their babies' lives meant that few people had met and interacted with their baby, and parents reported sadness over this. Further, parents had a desire to know more

about their baby themselves and remembering, talking about and reflecting on their baby's life appeared to be a way in which they got to know their baby better. These approaches gave parents a clearer and ongoing identity for their baby.

Parents described the need for their baby to be seen both literally and figuratively. Parents had used many photographs in their funeral services and some had commissioned a gravestone with a picture of their baby on it. Parents described how they treasured pictures that showed their connection with their baby. Special pictures included where they were cuddling their baby, grandparents and other siblings with their baby or holding his/her hand. Most parents felt pride and pleasure in the photographs of their baby. Most interviews were conducted in the parents' homes and I could see photographs of their deceased baby displayed. Photographs appeared to provide a tangible identity of their baby, for example this father referred to the precious nature of pictures he had taken:

"We took those photos and she had her eyes open, looking at you and stuff."

Parent 7, Father

One parent had a range of photographs, none of which she found easy to look at. Her baby had visible symptoms of the birth injury sustained and care escalation that were disfiguring and traumatic to look at both in life and in death. However, she did not want to dispose of the pictures. This parent had thought about the memories she had in the form of photographs and it caused heartache that these photographs could never be expanded upon; her collection was finite as recounted in the following extracts:

"It's sad because I've either got pictures full of tubes, everything all over her or I've got pictures of no tubes but it's very obvious that she's no longer alive. There's no in between, I find that very, very hard, that's what I personally find hard. I'm never going to have any more pictures, what I've got is what I've got, that's it. I do find that hard." **Parent 5, Mother**

"When you have all these pictures that's it because you're never going to get any. You're never ever then going to have any more advance ones made,

them growing up, the gorgeous baby ones, newborn ones, ones through stages.” **Parent 5, Mother**

Most parents shared photographs of their baby with me during the interview; some asked if I minded seeing the photo. They were animated when showing their baby to me and offered multiple photographs. It seems likely that parents did this whenever they talk to someone new about their baby and through the pictures, they can make their baby known to others.

“Can I just show you a picture of her? I wear her on me (locket), that’s the day of the funeral, I just feel it’s very important to show you.” **Parent 5, Mother**

Reflection Point 6.11: being shown photographs

I was grateful to be able to see pictures, yet I had no preconceived expectations of this. Looking at a photograph of their baby helped me to connect with their story; their baby became more real to me once I had a visual. I felt that being shown a photograph of their baby was another privilege extended to me and it was a further indication that we had established rapport and trust within the interview.

Parents remembered their babies in a range of ways to keep their identity at the forefront of their lives. All parents had been involved with active memory making at the end of life and left the NICUs with a memory box, which was treasured. Some parents looked at the memory box frequently and other parents put it away, unable to face the contents. Those that had not used the memory box, felt certain they would in the future and were appreciative of it. The following accounts highlight the value of the memory making:

“The neonatal team had done all his memory box and everything; they really looked after me that way, the lock of his hair and things like that. Yeah, it expands every day... Yeah, I find his memory box is very useful. It really helped me. It wasn’t something you had to look at, at the time, but it’s there for later on.” **Parent 1, Mother**

“We got footprints, memory box and all that kind of stuff and a lock of her hair.” **Parent 7, Father**

Some parents visited their baby at the cemetery to keep their baby's identity current and the visit itself appeared to offer comfort. Parents saw this as time to be with their baby and some said that they talked to their baby, for example:

"He is still a big part of our life you see, we do a lot of things based around him, like for his birthday we went away, and we always visit the cemetery."

Parent 1, Mother

The collective narratives revealed the strong parental need to reinforce the identity of their baby in the absence of their actual presence. This need was not just for themselves but for friends and family and to introduce their baby to people unknown. Parents felt passionate about the ongoing presence of their baby in their lives, through discussion, memories and a permanent place in the family. Maintaining their baby's identity was an important way in which parents coped in the time after their baby died.

6.6.2 Talking with a purpose

Parents' needed to talk about their baby appeared to be a strong compulsion and a coping mechanism that facilitated their grief; this need to talk emerged from the collective narratives. Parents were aware that they needed to talk, they felt like they could not help or control this need, especially in the early months post-bereavement. Parents described that they quickly developed an awareness of the discomfort in others, even family and friends, when they talked about their baby. They highlighted various encounters where people would change the subject or suggest that parents needed to distract themselves from focusing on their baby. Parents described being attuned to observing signs of non-verbal discomfort, such as, looking away, use of mobile phones and people physically moving away. Parents would take this as their cue to stop talking but they were then left with disappointment and unmet needs as the following extracts describe:

"It's like whatever, it's a taboo subject, it's very, very taboo. And I even find now, if I start mentioning, I can see them, 'oh God, please don't', because they don't know what, they don't know what to say. They have no...and sometimes

they'll run away from you and they'll avoid you, they're scared." **Parent 5, Mother**

"My Mum is very close, she's always round here, my sister's around the corner but we don't really talk about her, do we? I think the shock of my Dad, it kind of threw our baby out of the window a little bit. It wasn't easy to grieve for her." **Parent 3, Mother**

Parents were self-aware about their need to talk to experience catharsis. They noticed that they had a need to talk but also a need to keep repeating the same information. Parents did not recount their baby's lives from start to finish but were most likely to want to talk about a small aspect of their baby's life, care or personality. They also felt a need to talk about how they were feeling without their baby and experiences they were having during their time after the death of their baby, for example:

"I think you always need someone there to talk to when you're feeling down." **Parent 1, Mother**

When parents were able to talk about their baby to others, it helped their emotional well-being, but only if the person they were talking with was engaged and appeared interested. Parents indicated that information about their baby was privileged information and unwilling listeners were undeserving of that information. However, in contrast, all parents appeared to have an innate desire to make their baby known, even in death (discussed in Chapter 6.6.1.), for example:

"People's reactions are strange aren't they? Not strange but very, very different, you've had some amazing reactions from people that you weren't really expecting. And then you get other people that we expect a bit more from and they pop round or something like that but they won't even mention, they just try to avoid the subject altogether. And I think that's probably just standard for dealing with somebody that's gone through a bereavement." **Parent 7, Father**

"I think we're quite open, we'd like to talk about it." **Parent 6, Mother**

Reflection Point 6.12: catharsis from the interview

Once the audio recorder was switched off at the end of the interview, most parents said how much they had appreciated being able to talk about their baby in this way. Many said they hadn't recounted their baby's journey and their experiences fully in this way before and that some of the experiences and emotions had been shared for the first time in the interview. Some parents said that no-one had ever been this interested in what happened to them. From what parents had said previously about the cathartic nature of talking to people about their baby, I can surmise that talking to me in the form of an interview was also cathartic.

The need to talk was an ongoing necessity for parents, which they thought would continue. This subordinate theme of 'talking with a purpose' is interlinked with the previous theme in Chapter 6.6.1 of 'wanting their baby to be known' as it was through being able to talk that facilitated the identity of their baby.

6.6.3 Family, friend and peer support

The key mechanisms of support described by the collection parental narrative were family, friends and peers and these are the subject of this subordinate theme. However, parents' anticipated key supporters at times added to their grief experience. Parents described that family, friend and peer support were instrumental to their emotional wellbeing both in hospital with their baby but also afterwards in their grief journey. This discussion will first consider parents' narrative about family support and then, friend and peer support experiences.

"We've had support from family and friends. On a bad day, we talk to each other." **Parent 3, Mother**

In most circumstances, parents described family members, especially their own parents, being supportive right from the birth of their baby. Family members drew around the parents and baby to offer comfort, support and practical help. Some mothers described how they knew something was wrong with their baby because when they woke up from their general anaesthetic their family were present, for example:

“I remember opening my eyes and my mum was round me and my sisters, and my brother. I knew, I didn’t know what, but I just knew something wasn’t right, you wouldn’t normally have that, and I remember saying to my mum, ‘what’s going on?’” **Parent 5, Mother**

“That’s how I knew something was wrong. My Dad was only there and my Mum wasn’t. And I thought, well something must be wrong because half the family are here and they wasn’t when I went down.” **Parent 1, Mother**

Most of the parents described the death of their baby being a closed, intimate affair with just themselves and sometimes siblings. Grandparents and other family were not there for that period, presumably by the parents’ choice, but the reason for this was not mentioned in the interviews. However, grandparent support appeared to be crucial in the early days after the death of their baby. The act of coming home was difficult, and some parents discussed how family eased this transition a little as highlighted in the following accounts:

“Your mum was here as well, wasn’t she and if we didn’t have her here we would have just come back to an empty house, that would have been even harder.” **Parent 7, Father**

I didn’t really have any support apart from my family and we did move back here with my Mum for two weeks. **Parent 1, Mother**

In Section 6.5.2, parents’ accounts of how their family were sometimes unsupportive were highlighted, however, for the majority, family support had been significant in their ability to cope with life in general. Family helped with practical support and caregiving to other children but grandparents were particularly important in being an emotional support mechanism. Some grandparents had been instrumental in aiding parents seek further professional support by advocating for them at a time when they could not advocate for themselves. For most parents, family members were described as a listening ear and were most likely to be patient with the need to talk about their baby and their emotions, for example:

“My Mum is very close, she’s always round here. My sister’s around the corner.” **Parent 3, Mother**

“My Mum is a very strong person. Like at the hospital, my partner’s Mum just fell to pieces and the more she cried, the more I got upset and my Mum was like, I don’t like being like that because I have to be strong for you. So, she doesn’t cry after. So, I talk to her a lot about it.” **Parent 1, Mother**

“I speak to my husband and Mum. Actually I speak to my mum more than my husband. I speak to my mum on the phone most days.” **Parent 2, Mother**

In Section 6.5.2, isolated from social groups, parents revealed how friendships had changed after the bereavement but occasionally friendships had endured through the bereavement and grief. Many friendships however, had ceased abruptly or slowly disappeared. Most parents developed new and crucial friendships with peers from a similar situation and this was the most helpful mechanism in their lives. Aspects of finding peer support are discussed later in this chapter.

“I don’t know if this is a possibility, but I remember thinking this lots and lots of times, especially when I met my friend and I only ever met her because the bereavement team did the coffee thing at Christmas. I would have done anything, absolutely anything for another mother’s number, even if that was just text.” **Parent 5, Mother**

The friendships between peers who had also had a bereavement allowed for unfiltered conversation without the smoothing over of grim details. Emotions could be discussed in their ugly reality and when parents experienced thoughts that family and other friends might recoil at, these friendships could be sustained through this as illustrated in the following extracts:

“I’ve made quite a few good friends through the group that I see all the time. I have my friends outside of the group but it’s nice to have someone when you go out to understand what you’re feeling, and it has really helped me.” **Parent 1, Mother**

“I met my friend who I’ve become very, very close to. I remember saying to the bereavement nurse, ‘I know I’ve got you, but this is your job’. I remember saying, I’m not going to phone the bereavement nurse at silly o’clock.’ I want someone that goes, ‘I know because I was doing it last night, I remember doing that’.” **Parent 5, Mother**

Peer support was an issue that arose across the collection of parental narratives. Peer support in this context, is described as support from another person who has also experienced the death of a baby. Not all parents accessed peer support, but they had all considered it. The impact that peer support had on their lives was a reoccurring narrative. Parents did not discuss peer support during the end of life phase of their journey, therefore, the discussions of peer support are related to post-bereavement.

“I felt like no one in the world could ever understand what I had...but there’s hundreds of women in, not the same situation, but knows. I remember thinking for me personally, that would have been the most beneficial.” **Parent 5, Mother**

Reflection Point 6.13: lack of peer support on NICU

From the end of life narrative that parents shared, there was no mention of peer support on NICU. I can only surmise that they were so overloaded at that time with emotions, anxiety and decision-making that they were unable to form connections with other parents on NICU. However, from my own experience of being a nurse in the setting, observing parents in this context, I have often seen parents engage in peer support until their baby is very ill. I have then observed parents withdrawing from their peer connections, not wanting to hear of friends’ babies improving and doing well. This may have been a factor in this lack of narrative.

Parents who utilised peer support accessed it in a range of formats. Some used telephone support initially at a time of crisis and others went straight to an organised SANDS peer support group. Another parent attended a Christmas coffee afternoon organised by the NICU. From these groups, crucial peer friendships were formed over time, so that eventually, parents had the support of a group session and one-to-one connections where they were supported and were also the supporter. Four of the parents did not seek out or use peer support, although they were aware this support

existed. For some parents, the organised groups did not appeal to them. Fathers did not utilise peer support and some mothers described how the peer support groups were unsuitable for their partners, for example:

“My partner finds it very difficult to talk to anyone about it. That’s his way of dealing with it. And I can’t argue with that, I just, everyone has different...he has gone into quite a depression.” **Parent 1, Mother**

“There needs to be something for fathers. My husband was not able to go in the day there were no evening and weekend sessions. He didn’t find SANDS helpful, mostly women went, and he didn’t see the situation in the same light as the women did. Just a couple of men were there, and they didn’t say much, but men don’t want to talk like women do. Some other ladies I see say their partners didn’t have support or have connections with other fathers. Maybe a male SANDS is needed; my husband can’t be the only one in this situation.”

Parent 2, Mother

“I didn’t want to go online to SANDS and talk to someone in Oxfordshire or someone who lives in... this is my door step and I wanted someone who has lost someone living in this area.” **Parent 5, Mother**

Parents described being given limited information about peer support groups when they left the NICU but not details of groups that were local to them. Some parents had not read the leaflet and they did not think about support groups until they were at a crisis point and their emotional well-being was at an all-time low point. This crisis prompted support seeking from a family member. Some parents attended a SANDS group and found immediate acceptance, despite being nervous about going. The groups varied in facilitation but were mostly run by a bereaved parent of some longevity and experience. Parents described a sense of being able to relax, be themselves and not needing to put on a façade of feeling okay, for example:

“So I started going to SANDS a couple of months after, 2-3 months. This was when I’d just started going out of the house. I went to as many as I could, a few different ones around the area, for about a year. Then I settled at the local one. I met people there that I see now.” **Parent 2, Mother**

“In the January, we started attending SANDS and I’ve been going ever since. That really helps me to deal with it. The first time I went I wasn’t really looking forward to it. We went, and it’s just to listen to everybody’s stories and to know that people understand the way you’re feeling. It’s not abnormal and I’ve made quite a few good friends through the group that I see all the time. I have my friends outside of the group but it’s nice to have someone when you go out to understand what you’re feeling, and it has really helped me.” **Parent 1, Mother**

One of the mothers who attended a SANDS group felt it had a limited timeframe. This mother found that when a new group of parents joined the group, she did not feel connected to the dialogue anymore. The discussions were not helping her because they were taking her back to feelings she did not want to revisit. She perceived there to be a gap in support groups after the initial months, as recounted in the following extract:

“I stopped going to SANDS when a bunch of new ladies came, and their grief was very raw. It’s different from the longer-term point of view. I felt that the new ladies didn’t want to know about my baby. They couldn’t hear it, I didn’t want to go again after that. I saw SANDS as my baby time and I was very disappointed that was gone. There’s possibly the need for a longer-term group. Some others don’t feel the need to keep going, but some do.” **Parent 2, Mother**

One mother attended an event organised by the NICU, all parents whose baby died in the last 12 months were invited for informal chat and family-orientated activities to remember their baby over Christmas with staff from the bereavement team. This mother formed a connection with another mother over coffee and they exchanged telephone numbers. From then on, these two mothers texted, then spoke and met up regularly. Eventually their partners joined the mothers and they made their own regular arrangements, becoming one another’s primary supportive mechanism. For the mother in this study, she felt that this peer support was her daily lifeline and that it kept her from becoming mentally ill as detailed in the following account:

“I met my friend and ... I just feel like she was sent to me and I wasn’t going to go...To the point of I just don’t know where I’d be now, I don’t like to think about it actually.” **Parent 5, Mother**

Peer support groups or one-to-one peer support were not right for every parent in the study. Four of the parents chose not to seek this support mechanism. The reasons that these parents did not seek peer support was because either, it did not appeal to them, they did not want to be exposed in front of others or they felt they had sufficient support.

Parents that accessed peer support described the importance of context of death and made passionate statements about how their situation was unusual. Parents did not see their experiences as the same as someone who had experienced a miscarriage or stillbirth and they did not want their experiences compared with those parents. Some parents felt that other parents with different bereavements were in a better situation. The idea of comparison of different bereavements was an emotive topic for these parents and this indicates why a mixed peer support group might be problematic, for example:

“What I do find is that people suddenly say, ‘yeah, I know what you are going through because I had a miscarriage.’ No you don’t. Or ‘my friend had a baby at 24 weeks and he died’, it ain’t the same. I’ve never had a baby at 24 weeks but I’m saying, it’s not the same and people were going, ‘it is because when you’ve lost a baby, regardless of their size it’s the same’. And I’m going, I have to disagree, I’m sorry, I completely disagree.” **Parent 5, Mother**

For some parents, peer support groups or connections became the primary source of support and comfort. However, for the majority of parents, this was not the mechanism of support they wanted. Contacting and then attending a peer support groups was often born out of desperation, rather than a planned activity at a defined point in the grief journey.

6.6.4 Professional support

Professional support came in a variety of formats and it often had to be sought rather than being easily accessible. Each parent had experienced professional support in

NICU, in addition, most parents also sought professional support post-bereavement; a range of different professionals were involved in this. Parents revealed both supportive and negative encounters with health professionals and it was through some of the negative encounters that the full experience was revealed. This subordinate theme describes parents' experiences of professional support before and after the death of their baby.

Some parents described their interactions with in-patient midwifery and obstetric care. One mother described a mixed experience including positive and negative midwifery care. This mother encountered a midwife on the post-natal ward who did not seem to realise that her baby had a poor prognosis and was likely to die imminently. This mother is still hurt by the comments made to her and memories of these comments continued to intrude into her grief. Another parent was certain her baby died because of poor intra-partum care and decision-making, therefore, this mother reflected significantly on the experience of not being listened to. During labour, she knew that something disastrous was happening to her and her baby as she haemorrhaged, but she did not feel her concerns were listened to. Since her baby's death, this is something that has persistently inhabited her thoughts and complicated her grief journey as highlighted in the following account:

"I said to him 'There's something wrong, if I'm 5cm dilated, this is my fifth baby, I would know.' I would know. And he just said, 'I'm going to leave you half an hour and I'll come back'. So, I've stood up then to sort myself out and my insides have just emptied. Absolutely, emptied. So, I know, and I'm saying to this midwife, something is wrong, you need to get this baby out. The baby needs to come out now." **Parent 5, Mother**

"It can make you quite bitter, it can make you into a person that you are not. Comments, especially comments that are not correct, do and can have a devastating impact on your grieving process because your mind is different anyway, you cling onto these little comments, usually negative comments." **Parent 5, Mother**

"Then one of the midwives said, 'oh what's going on here, a party?' And I thought, well that's a bit heartless." **Parent 1, Mother**

Parents experienced rotating shifts during their time in NICU and this meant frequent changes in health professionals where parents needed to get to know and trust new nurses and doctors. Parents appreciated when they had consistency of care; they felt a relief when their baby and their history was already known to the health professional. Some parents perceived that continuity of care led to quicker intuition and detection of deterioration in their baby; one mother was always less anxious when a nurse she knew and trusted was looking after her baby. Unfortunately, continuity was a rarity rather than the normal situation and whilst all parents appreciated and understood the resourcing of care to some extent, this did affect their experience, for example:

“It helped to have familiar nurses around. The doctors at the NICU second time around were new to us. There’s nothing you can do to make this kind of news better, but we were told on the ward, not in a room.” **Parent 2, Mother**

“They said, ‘oh, she hasn’t had a very good night, we haven’t been able to get her sats up’ and one of the nurses I did know had had her and she’d just not been happy. This nurse was like ‘I don’t like this, I don’t like the way she looks, so I’ve asked for another CRP’.” **Parent 6, Mother**

Breaking bad news was an experience that many parents wished to share. These interactions were key moments in their baby’s life and parents could remember details including what, how and by whom the information was given. Parents revealed that as their baby’s poor prognosis was certain, the doctors they encountered went to great lengths to help them understand the truth of the situation, although, jargon proved to be problematic at times. Whilst this was a difficult reality to accept at the time, parents appreciated the candour on reflection; they saw this as an ultimately caring action as summarised in the following accounts:

“The consultants in our baby’s care, I think they were very straight forward, weren’t they? Obviously, they were very specialised. Yeah, they were very blunt. We didn’t need flowery conversations. We didn’t need to keep going over old ground either, it was just a case of let’s see things through.” **Parent 4, Father**

“Because I remember a couple of times being in the actual meeting rooms and I remember the doctors with their jargon and I’m saying to them ‘speak normal to me, just tell me how it is in layman’s terms’. And they do, they go ‘you know, she’s been deprived of oxygen, she has severe brain damage, she’s completely blind, completely deaf’. And that’s what I wanted to hear, I didn’t want to hear these big words because they mean nothing to me. You know, they’re straight with you, they really are.” **Parent 5, Mother**

Many parents described ongoing frustration at the conflicting information they had encountered from different doctors in the NICU. This was brought into sharp focus when some parents described receiving contradictory information about their baby’s survival, with one doctor suggesting that survival was possible and another categorically stating the situation was futile. These experiences seem to have intruded significantly into parental thought patterns after their baby’s death and driven the direction of parental grief at times.

“What I find, I do still find this hard, when you can speak to one doctor and then you could speak to another doctor in the same day, they’ll both obviously be the same on how poorly she is but then you’ll have one doctor saying ‘there’s not much more we can do’ and then in the next breath you’ve got another doctor saying ‘she just needs time’.” **Parent 5, Mother**

“In fact, the junior doctor, he was kind of saying, ‘well you can do this, that and the other’...And he was saying he’s got a duty of care to do whatever they can but then when I had a chat with the Consultant, the consultant said, ‘that’s fine we can withdraw treatment.’” **Parent 7, Father**

Parents wanted to feel their concerns and instincts were listened to, and there were crucial moments where one parent felt this did not happen. This mother had increasing concern for her deteriorating baby. She struggled with less visible medical staff on a Level 2 NICU and felt that communication was not regular or effective, for example:

“The Level 2 unit was a nicer environment, less intense, friendly staff but we didn’t see a doctor hardly at all, the doctors didn’t talk to us, and they didn’t listen to us. We were made out to be hysterical. Parent 2, Mother

Parents were forthcoming with praise for the health professionals and support staff that made their terrible experience in NICU a little better. Parents offered praise for the care and communication amidst the fraught, emotive end of life period. They revealed the difference compassionate care meant and they remembered it often, also remembering the individuals. One parent gave an example of where her partner was not grasping the reality that their baby was not going to survive, and one nurse sought who she thought was the most suitable doctor to speak to her partner:

“One of the staff nurses, and I was basically saying to her, lovely woman, I had a very good rapport with her, she was very honest with me. I remember just saying to her, I’ve got to let her go, I cannot do this anymore. But ... I couldn’t just say yes, it doesn’t work like that. I remember the nurse saying to me, ‘I agree with you now but obviously we can’t do this without your partner’s consent’. She was going to go out of her way to get who she felt was the best possible doctor to explain to my partner.” Parent 5, Mother

“We’re just still full of admiration for the doctors and everything.” Parent 6, Mother

“The NICU staff, all of them were so helpful. Yeah, they were really good. They were amazing. From the cleaning staff, I don’t know where they find them.” Parent 7, Father

The interactions that parents experienced in the NICU had a significant impact on their thoughts and grief once they got home without their baby. The positive experiences gave comfort as they mentally played memories of their baby’s life. However, the negative experiences appeared to impact parents more profoundly, lingering in their thoughts and affecting their emotions frequently. These negative experiences also had an impact on willingness to seek professional support once parents were home. Parents’ ability to trust in health professionals and expectations about communication were lowered for some parents.

"It floored me, it has changed me forever, I will never trust a professional again, ever. Never, ever, ever. I will never fully trust, never." **Parent 5, Mother**

Reflection Point 6.14: professional support through the parental lens

This section on professional support has been one of the most enlightening themes. In my role as a bereavement support sister on NICU, I knew the potential effect of negative experiences on grief, parents told me some similar stories when I visited them in my therapeutic role. However, bringing together parents' narratives and listening to each parents' negative experiences that had made their grief harder, was impactful.

Parents continued to have a range of support experiences once they returned home after their baby's death. Most mothers were still under the 28 days of midwifery care at this point. Otherwise, parents had no firm arrangements with any health professional once they went home. However, on leaving the hospital, all parents were offered a six-week appointment with their baby's consultant to discuss the cause of death and any arising questions. Some parents, dependant on which unit their baby died at, were offered contact with a Bereavement Support Nurse. Other parents felt deserted, with no idea who to talk to about the legal and practical arrangements they had to make whilst encountering early grief. As discussed in Chapter 6.4.4, these first few weeks were a time of fractured thinking and great distress. Therefore, it is understandable that professional support might be needed at this time. The following extracts highlight the gaps in professional support:

"There's no gelling between the NICU and where you go next. There's nothing." **Parent 6, Mother**

"I didn't really have any support apart from my family. There was no support really from the outside. The health visitor come round while I was pregnant and I always thought maybe they'd come back after, whether the baby is here or not. There was no contact with the health visitor." **Parent 1, Mother**

"I'd had a caesarean, I'd just lost my baby and still to this day, I've never heard from a midwife, I have never heard from a health visitor." **Parent 5, Mother**

Some parents had the experience of a one-off visit from a bereavement nurse or midwife in the initial few weeks and whilst they appreciated this, they were left frustrated why this could not be sustained. Parents were dissatisfied with this situation and they had no control over it, for example:

“Straight after, the bereavement midwife from the Level 2 unit visited but we never heard from her again.” **Parent 2, Mother**

Some parents were completely satisfied with the professional support they received. Parents described only positive experiences when they had regular contact and support from bereavement nurses. They recounted feeling clarity over support, from leaving the NICU, to what they might need after they got home. These parents felt in control as much as they could be and that requesting support was up to them, it was not mandatory. This is an important point, as discussed in Chapter 6.5.1, some parents needed to withdraw and isolate themselves as a protective measure. At times, that included not wishing to see professionals, as well as friends and family. Bereavement nurse support was highly valued by those who utilised it and the following extracts summarise the experiences:

“The bereavement nurse came on her days off, she was brilliant. She was by far the best person to speak to. But it was finished after 6 months. But she still came one year later, on his birthday.” **Parent 2, Mother**

“The information about support after was good. The nurse came to visit us; she kept in touch. Yeah, they gave us a full information pack and yeah, she did keep in touch. We got a Christmas card off her. They came when we wanted but we saw her just once. When she came, I think it was helpful. We sort of decided it wasn’t necessary for her to keep coming.” **Parent 3, Mother**

I still see the bereavement nurse now and again, not as much obviously. What we agreed was, when I first used to meet her, she used to come to mine but then I actually found that a bit overwhelming, it was a bit much. So, what we started to do was meet in a mutual setting, like we’d meet up in a coffee/tea room thing. But that does die down in the end but in the beginning, I have so

much to thank the bereavement nurse for. But she was very, very good at the beginning.” **Parent 5, Mother**

Some mothers described their concerns about their partner’s lack of time to grieve, their psychological distress and lack of access to support because of work and financial pressures. Some parents were aware of the professional support available for them, even though they were not under the care of a bereavement nurse. However, they decided that to date, they did not need it and felt in control of this decision, for example:

“My husband didn’t have counselling. He was working, you’ve not got the time, he could have done with that. At the moment, our support needs go to the bottom of the pile. I had a full year’s maternity leave after our baby died but my husband went back to work after 2 weeks.” **Parent 2, Mother**

“We haven’t had any professional support, we were told about it all and I read a little bit on the SANDS website and the TOMMYS website and I know that there are things, but we haven’t felt the need to go.” **Parent 6, Mother**

“But we know that they do regular services (memorial service) and those sorts of things but you know, we were doing it ourselves really.” **Parent 7, Father**

Some parents recounted their experiences with counselling post-bereavement, but this was not a therapy suited to all parents. Counselling was often sought after a time of crisis and distress. Access to counselling was facilitated by General Practitioner (GP) referral. Unfortunately, the type of counsellor needed was not always considered and parents had experiences with both general and bereavement counsellors; the road to access counselling was stressful and dissatisfying. Parents had to wait a significant amount of time on a list and there were some errors in administration and communication that caused distress. For most parents, once they had the right counsellor, it was helpful. The following accounts highlight parents’ experiences with counselling services:

“So, I went for some private counselling first, and I didn’t find that helped me, she wasn’t a bereavement counsellor, she was more of a general counsellor.”

Then the hospital rang me up with their waiting list for bereavement counselling so I think it was nearly August before I got to bereavement counselling. And I found it really, really helpful. It was about having the right counsellor.” **Parent 1, Mother**

“I tried counselling once but it wasn’t for me, I don’t think. I only went once, I haven’t wanted anything else.” **Parent 3, Mother**

One parent’s journey to access counselling caused undue distress and it affected her already tenuous well-being. When this parent eventually got to the top of the waiting list, she was called for her first appointment on the birthday of her deceased baby; a second appointment was then made for her on the death of her deceased baby. She asked to rearrange the appointment again and was told she was at the bottom of the waiting list for cancelling appointments. This mother could not fathom the lack of insight and compassion considering she knew her GP had included the dates of birth and death in the referral letter. Although this parent chose not to receive the counselling in the end, she now has an innate distrust of counsellors. This will affect any future need for counselling. Examples of this mother’s experiences are highlighted here:

“I even had a horrendous experience with the counselling. I didn’t want counselling, I didn’t know if it was going to be beneficial to me. I was like, I can do this, I think I was that scared then of professionals because of how I’d felt I’d been (treated).... You never guess what they said to me? ‘You’ve cancelled twice now, we’re going to have to put you to the back of the list’.” **Parent 5, Mother**

“I didn’t want counselling at first but then I realised that I would benefit from it. I got counselling through work, then I needed extra sessions. I feel like I could still do with some. I saw an Occupational Health counsellor.” **Parent 2, Mother**

Having the right kind of counsellor appeared to be important, the skill of bereavement counselling was not universal, and parents felt they should not have to be seen by a general counsellor when their focused need was clear. The collective parental

narrative recounted an overall feeling of lack of control over this aspect of seeking support.

Support from the local GP was necessary for all parents, sometimes for a sick note, or for mental ill health and somatic complaints throughout the grief journey. Many parents also sought advice and referral from the GP in relation to future pregnancy planning. However, parents encountered a variety of experiences with some GPs not being aware that their baby had died leading to disastrous interactions that left parents unwilling to see the GP again. Some parents did have positive GP experiences. The range of experiences are represented in the following accounts:

“I remember saying, ‘if you’ve not got the time to read my notes before I walk in, I don’t want to see you.’ I stood up, went out and said I don’t ever want to see her again, I was so upset.” **Parent 5, Mother**

“The GPs were just dreadful, weren’t they? So, they just didn’t have a sense of what was going on, you ended up changing GP surgery.” **Parent 7, Father**

“Our GP was really good.” **Parent 2, Mother.**

Parents recounted a need for GPs to be informed of their recent bereavement and that they expected careful and sensitive handling, although this was rarely the case. These experiences added to the growing mistrust of professionals that some parents expressed.

The superordinate theme of ‘trying to survive’ explored parental narratives over the diverse aspects of identity, being able to talk, support from friends, family, peers and professionals. All parents needed a range of strategies to survive their early and later grief experiences.

6.7 Theme 4: Routes to an improved future

Exploring parents’ perceptions of their support experiences and asking them to ascertain what they thought would be helpful to future parents was a key objective of this study. During the interviews, most parents naturally progressed to future care improvements. Parents knew instinctively what had been useful for them, what the

shortfalls were in their own supportive journey and what could be helpful for future bereaved parents. Parents described wanting to be invested in aiding future services and felt passionately that support should be easy to access, with a wide range of options available. This superordinate theme relates to routes forward in care strategy according to the collective parental narrative. The three subordinate themes that are explored arising out of routes to an improved future are: 'communicating clearly and with care', 'reframing the NICU experience' and 'mapping appropriate support'.

6.7.1 Communicating clearly and with care

Communication was a prominent feature across parents' accounts even though they were not explicitly asked about communication. Parents reflected on and shared their own experiences, appreciated the areas of care or support that went well and those that did not go well and caused emotional distress. These experiences enabled them to consider how interactions could be developed to make future experiences better. Parents were able to describe elements of an optimum version of their interactions from their perspective. This subordinate theme will explore four areas that parents raised: parents need to be listened to, discussions should be jargon free, the need for a planned, clear and consistent messages between health professionals and communication should prepare parents for what to expect at the end of life.

Most parents described one or more conversations with health professionals where their worries, concerns and questions were not listened to. In most situations, parents referred to medical staff not being attentive or listening. Parents perceived that they were 'talked at' by doctors and that dialogue was not always encouraged but they recognised that experienced professionals were giving them vital information. In addition, parents identified that empathy was vital in all communication and if it was not conveyed it had an effect on relationships. These issues are highlighted in the following extracts:

"But we didn't see a doctor hardly at all, the doctors didn't talk to us, and they didn't listen to us." **Parent 2, Mother**

"There was one consultant and she was, she might have known everything that was necessary to be known knowledge wise, but she had absolutely no

empathy whatsoever. It was just a mechanical problem. Well, she really annoyed me, didn't she? I didn't like her at all to be honest." **Parent 4, Father**

Parents wanted to be empowered to not only ask questions in a conversation, but to be able to raise concerns about changes they had noticed in their baby or worries that they had. Some parents noted that during their baby's stay on NICU, opportunities for questions with doctors were rarely made available. However, when it came to resuscitation conversations or withdrawal of treatment discussions, suddenly parents were expected to be active in the decision-making process and were listened to. Parents lamented a more consistent partnership in this aspect of communication, where their worries, concerns and wishes were listened to across the trajectory of their baby's life; this was their recommendation for future parents. Examples of their experiences in this area are highlighted in the following accounts:

"And it was in the morning that they started talking more about letting her go basically and that's what we decided to do, well we didn't really decide..."

Parent 6, Mother

"And then they rang us just before midnight saying we're resuscitating her, you need to get here. They hadn't discussed resuscitation with us, only that phone call when we was on our way back." **Parent 3, Mother**

Not all parents felt able to assert themselves in their interactions with health professionals. Parents found NICU to be an intimidating environment and they had many questions. However, parents had a clear instinct for changes in their baby's condition because they sat with their baby minute-by-minute, most of the day, every day. Parents described feeling that their parental intuition and observation was undervalued. One parent used what she overheard in ward rounds to answer some of the questions that she had that she was not able to ask. This parent had medical experience and knew that her need for answers to questions was enhanced. The following examples recount parents' thoughts about this:

"I think the only time that gets hard is when like, I sat in on a lot of ward rounds, I was in that NICU a lot and I sort of wanted to be in on those ward rounds because when I hear the doctors talking to one another, doctor to

doctor, it gave me a lot of confidence that they were having the same thought processes and questions as I would about other clinical things.” **Parent 6, Mother**

“They didn’t listen to my opinions.” **Parent 2, Mother**

Parents found that even over a short period of time they assimilated some of the jargon of NICU. Words such as CRP (C-reactive protein), MRSA (Methicillin-resistant staphylococcus aureus) and CPAP (Continuous Positive Airway Pressure) became terms they heard and used, however most parents did not actually understand the meaning of these terms. Therefore, when it came to the difficult conversations about prognosis, resuscitation and withdrawal of treatment, the need for doctors and nurses to use jargon-free and abbreviation-free language was highlighted. Parents’ experiences were that both doctors and nurses continued to talk sub-consciously in their own language, even in the crucial conversations. Parents recommended that for communication to improve for future parents, that simpler, lay-person vocabulary needs to be adopted. Misunderstandings in communications at fundamental points were disastrous, and parents had a desire to save future parents from the ongoing questions and uncertainty that some of them had to live with in their grief journey. For example:

“Because I remember a couple of times being in the actual meeting rooms and I remember the doctors with their jargon and I’m saying to them, ‘speak normal to me, just tell me how it is in layman’s terms’.” **Parent 5, Mother**

The need for planned and consistent communication between health professionals was passionately recounted by parents and advocated for those in the future. Many parents had experienced conflicting information at crucial points, and they had felt confused by this; they remained bewildered and distressed by this on reflection. Parents revealed their experiences of badly planned resuscitation conversations as an example of where this had gone wrong and they believed this could have happened in a better way. When discussing recommendations, one parent described being asked about a resuscitation decision for his baby, yes or no, on the telephone whilst driving. This father felt this is something that should not have happened to him

and nor should it happen to future parents. On reflection, this father was certain that health professionals could predict the need for this conversation to take place earlier, in a better way and environment:

“It’s consistently been just not having the right information, which to be fair, it isn’t like the human race isn’t experienced in having babies or even babies that aren’t very well.” **Parent 4, Father**

Parents navigated the journey into end of life and eventual death of their baby with trepidation and fear. It was difficult for parents to look ahead and imagine what was going to happen. Some parents felt that their fears and worries could have been alleviated slightly by having prior information about what to expect in the dying process and what to expect of their baby’s body after death. Some parents found the reality shocking and would have liked to have been prepared for this. Further, they had a desire for all parents in the future to be prepared for this eventuality. Parents thought that honest, sometimes graphic detail of what to expect about the death and body of their baby would have been helpful to them and that it would be beneficial for future parents. The following account summarises this need:

“So then I remember saying to my partner, then saying to the nurse, my biggest fear was rigor mortis, I was petrified of it. And she said, ‘newborn babies don’t get it’. I remember just feeling utterly relieved, I had visions of holding this baby, I was like, I can’t do this. And I remember just thinking, I’ve got to do it I knew she was dead then obviously and she was nice and clean and yeah, but she just bled profusely. I’m traumatised by this. It’s all I see. I mean, she just bled...I remember thinking even death has shown her no dignity.” **Parent 5, Mother**

Parents needed all communication at the end of life to be clear and to be conveyed with care and sensitivity. None of the suggestions that parents made were generated from unrealistic expectations or were unreasonable. Some of the parental recommendations only highlighted current best practice that should have been happening but was not occurring in all situations.

6.7.2 Reframing the NICU experience

Reframing the NICU experience relates to the change needed in health professionals' expectations of parents post-bereavement. The NICU experience should end when parents leave the unit after their baby's death and parents should not be expected to return for any reason unless they wish to do so. This subordinate theme arose from the collective parental narrative about their experiences of being compelled to return either for a death certificate, a visit to the mortuary or for the post-bereavement consultation. Parents described passionately that this was an untenable situation, and that it was preventable and unacceptable. Parents who described this issue were clear that once their baby had died, they categorically did not want to return, nor could they foresee a time where they would want to. Five of the parents in this study had been required to return for one of the reasons previously stated. This situation caused dread, significant distress and potentially complicated early grief processes, for example:

"And another thing, they could have done better, was when we went to visit our baby to take some clothes and stuff, after she died, and they made us go and wait on neonatal intensive care again, didn't they, for somebody to come down from the morgue to come and get us. Which, there was no need for us to go back on intensive care. That was days afterwards." **Parent 4, Father**

"The review appointments were helpful. Two weeks after our baby had died, my partner had to go away to work and because of that he was only available on the weekends. So, the review had to happen on NICU." **Parent 2, Mother**

Returning to the NICU for a death certificate appeared to carry an extra emotional burden. Parents found the formality around death certification to be distressing because of the wording, the process and that it would lead to having to register the birth and death of their baby together. Parents revealed that returning for the death certificate often led to hours of waiting for a doctor to come, finish the certificate, and explain what was written in it. Because of the distressing circumstances of that day, few parents remembered what the doctor or nurse had said to them. Parents felt this whole process was unnecessary and that a death certificate should always be available to take when parents initially left the unit. Parents in this study wanted

future parents to have a better experience and less distress over this matter. One father summarised it in the following way:

“You just want to get it and get out. We had to go back to neonatal unit to get the certificate. We had some hassle. It would have been nice not to have to go back to neonatal to get the death certificate.” **Parent 4, Father**

Parents had strong opinions that any return to the NICU for any reason was unnecessary and that future parents should be saved this distress. Some parents lived far away from the NICU, so this was also an inconvenient task as well as distressing. This subordinate theme explored the experiences of returning to the NICU post-bereavement that led to recommendations from the collective parental narrative to reframe the NICU experience as having a definite end point. This outcome from the narrative has implications purely for organisation of appointments that is a reasonable expectation for parents to have.

6.7.3 Mapping appropriate support

Living through end of life and experiencing ongoing grief means that parents are well placed to describe their own support experiences and influence future services. This subordinate theme considers both the type and timing of supportive interventions that parents perceived should be available. The timing of supportive interventions was of importance to parents as they described a ‘map’ of their experiences. This theme will also explore parental recommendations on access to a bereavement nurse for all families in a similar experience, facilitated peer contact and support later in their grief journey. A common experience described is highlighted in the following extract:

“After a few weeks, everyone just disappears and you feel like, that’s it now. I’m on my own. There’s no support from anywhere else, you have to go out and find it yourself and you find a lot of the families at SANDS feel the same.”

Parent 1, Mother

Parents highlighted that mothers and fathers should have equitable access to all the support services on offer to bereaved parents. Some mothers described their concerns about their partners who had to function with the realities of work life while

still immersed in their grief. Some mothers provided suggestions such as specific support groups for fathers as the following extract recounts:

“There needs to be something for fathers. My husband was not able to go in the day. There needs to be evening and weekend sessions, he did try but he didn’t find SANDS helpful. Mostly women went and he didn’t see the situation in the same light as the women did. Maybe there needs to be a male SANDS. My husband can’t be the only one in this situation.” **Parent 2, Mother**

Parents were aware through their own experiences of seeking support that support availability was dependent on location and local commissioning. Parents were passionate in voicing their concerns about all bereaved parents having access to an equitable range of support services. One parent had encountered support being withdrawn at six months and so had to find alternatives as described in the following extract:

“Bereavement nurse came, she was brilliant. She was by far the best person to speak to. But it was finished after 6 months.” **Parent 2, Mother**

Parents described the importance of all parents having access to a bereavement nurse and that bereavement support should be a funding priority. Parents’ recounted their experiences of bereavement nurses who were able to listen, offer practical advice, offering some common expectations parents could have from a grief experience and signpost and refer parents to other professional support. Parents highlighted the need to have the telephone number of a professional, ideally a bereavement nurse. This provided a sense of comfort and someone to turn to during difficult time periods. Parents who had experienced this, described that it was pivotal to their well-being at some point in their grief journey. Parents described a range of examples where their bereavement nurse was able to answer questions about their baby’s life and death, help translate an investigation report or listen and guide their experiences of grief. Parents highlighted that the bereavement nurses visited in the day, which in many instances excluded fathers from this support. Parents who did not have a bereavement nurse were aware that those services existed in other locations and wanted the opportunity to access this type of support. The following extracts highlight parents’ accounts for future parents to have this support:

"I would have liked a bereavement nurse because it took me, I think it was March, before I even decided that I needed counselling and there was no one there to say to me, I think you need to talk to someone. And it would be nice, you know, for someone to come round and maybe talk to you about it and say, maybe you do need a little bit of help or you do need to talk to someone with bereavement experience." **Parent 1, Mother**

The bereavement nurse came ... she was brilliant. She was by far the best person to speak to." **Parent 2, Mother**

"The bereavement nurse said if I needed her, to ring and then I think she left it a while and then rang me and said did I want her to come and talk." **Parent 3, Mother**

Parents described being comforted when a bereavement support service was standard care immediately after the death of their baby, because support was available before asking for help and before reaching a point of distress. Parents that spoke of this as a recommendation wanted the bereavement nurse to be available from the point of death. This was crucial to reduce the sense of abandonment by professionals. Parents also wished future parents not to have to search for some means of support. One mother summarised in the extract below how the bereavement support service brought to her life, yet not all parents had this service:

"I have so much to thank the bereavement nurse for. I just built up this really good... But she was very, very good at the beginning. Not even that, the things that I didn't understand, that she was aware of should have happened, she was doing things for me that I wasn't even..." **Parent 5, Mother**

"There's no support from anywhere else, you have to go out and find it yourself and you find a lot of the families feel the same." **Parent 1, Mother**

Peer support was a strategy that was described as imperative to coping for some parents who perceived that this should be facilitated by the NICU. One practical option would be for NICUs to introduce the nearest peer support group to the family

residence. Another suggestion from one parent was to have previously bereaved parents who volunteered their phone number for a newly bereaved parent to contact if needed. This suggestion carries an emotional burden for the parent offering the support which necessitates a support network for the volunteers. The parent suggesting this option described meeting another bereaved parent at an NICU event which she valued and perceived was crucial to her ongoing emotional well-being. This parent's suggestion was reinforced by other parents' experiences of making personal friends at peer support groups and going on to swap contact details, for example:

"I don't know if this is a possibility, but I remember thinking this lots and lots of times, especially when I met my friend and I only ever met her because the bereavement team did the coffee thing at Christmas. I would have done anything, absolutely anything for another mother's number, even if that was just text."

Parent 5, Mother

The final recommendation that parents made related to the timeliness of supportive interventions. There were some differences in when parents considered support was needed, however there were also some similarities and parents' rationale for timeliness of interventions were supported by their examples and experiences. Parents had recommendations over the early bereavement period and later in the grief journey, but this cannot be measured in weeks and months. Most parents described the time period after the funeral when people that had been surrounding them initially disappeared. For some parents, family also retreated at this point. By the time two weeks had passed after their baby's death, parents found themselves alone and often unsupported. Further, mothers would be on maternity leave for some time and alone at home, whilst fathers would have returned to work and being expected to function in their jobs as normal. This time period was a point at which parents recommended early support services should be offered, for example:

"After a few weeks, everyone just disappears and you feel like, that's it now. I'm on my own." **Parent 1, Mother**

"I remember it took me a few weeks to read the leaflets, to look through it. I did that very quietly because I was on my own." **Parent 5, Mother**

Parents' narratives described experiences and recommendations for later support. Parents perceived that there were unrealistic societal expectations about how they should be getting over the death of their baby within a 6-12 month time frame. Yet, parents described that this was a time where the reality of life without their baby was starting to be fully understood and a time that support was vital. In addition, parents with support from a funded bereavement service, such as a bereavement nurse, stopped at six-months following the death of their baby. One parent revealed that she was only beginning to process her experience and the loss of the bereavement nurse was difficult. Time mapping of future services should consider individual needs. The following extract highlights ongoing need for support:

"I think funding for bereavement support needs to extend past the 6 months. Six months feels like a second. If my support had ended there, I would have been in trouble." **Parent 2, Mother**

Parents had differing support experiences and they recognised that not all parents would want the same support. Parents advocated for a bereavement nurse for all parents from time of death, counselling by an experienced bereavement therapist as needed, peer support with facilitated connections and access to equal support for mothers and fathers. Although the collective narrative guided the timing for support, there should be individual flexibility.

Reflection Point 6.15: altruism towards future bereaved parents

Parents' desire to discuss their experiences and suggest a range of approaches for support suggests that they were ultimately altruistic despite the burden of their own emotions. I was surprised and affected by the compassion demonstrated for future families that the parents in this study would never meet. These parents were not purely concerned about themselves, they were philanthropic in their desire to see improvements in services for the future.

6.8 Surviving the Sandstorm: The Neonatal Grief Sandstorm visual tool

The visual tool presented in Figure 6.3 draws on the themes that emerged from the analysis of parents' narratives and aims to represent how they survive the death of their baby and navigate life afterwards. The purpose of this tool is to provide a relatable way for both professionals and bereaved parents to visualise and discuss common experiences of bereaved parents. The Neonatal Grief Sandstorm (NGS) represents three core areas of difficulty for parents who are grieving: falling in, sandstorm and on the ground. The visual tool is rationalised, discussed and applied to parental experiences in Chapter 7.7.

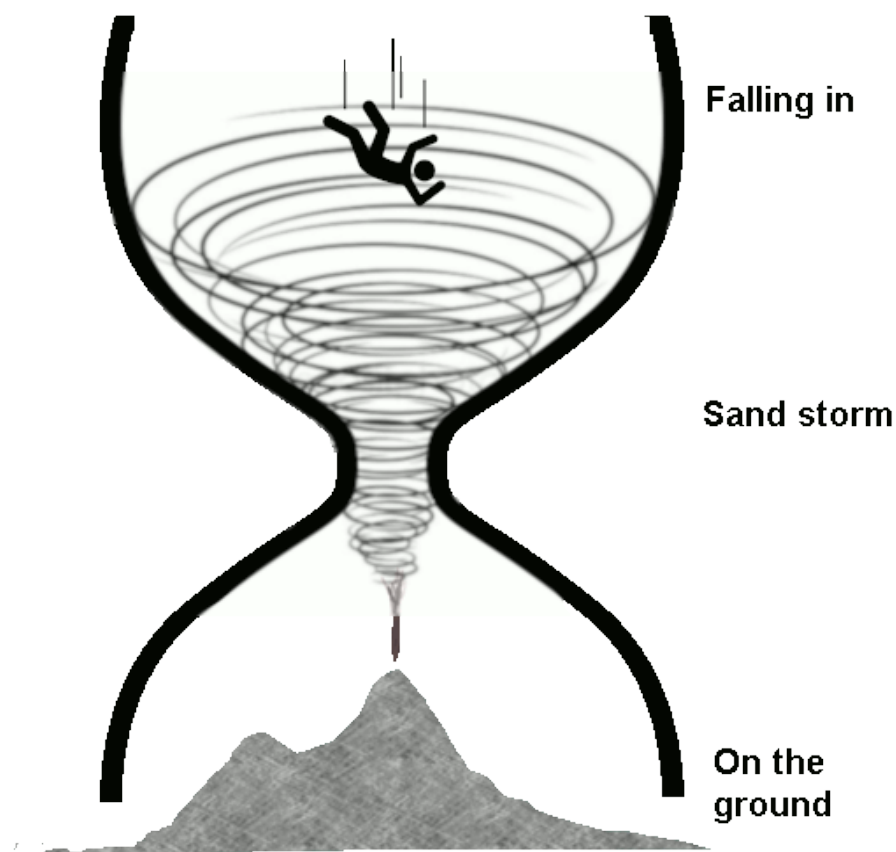


Figure 6.3: Surviving the Sandstorm: The Neonatal Grief Sandstorm

The initial concept that emerged from each parent's narrative centres on a black hole. The collective narratives spoke of grief before, during and especially after the death of their baby and their descriptions were of darkness, loneliness, lack of control, vastness and depth. However, this concept of a black hole did not represent the full experience, only the initial experience of grief. As data analysis and interpretation progressed, the NGS emerged.

'Falling in' the sand timer is a shocking, dark and frightening experience; it quickly leads to a narrow space. 'Falling in' can occur anywhere along the palliative-end of life trajectory as parents begin to experience anticipatory grief. As with the earlier discussed black hole analogy, it felt outside of parental control, the sense of falling was terrifying and parents could not influence the direction they were locked into. Once death had occurred and parents had fallen into the grief experience, they moved reasonably quickly to the narrow part of the sand timer and in that space, they were in a sandstorm.

The 'Sandstorm' was chosen to represent the uncontrolled turmoil that parents' lives were at this time, with confusion and a lack of sight ahead both metaphorically and in daily life. Parents appeared to withdraw into themselves in the sandstorm for protection. For some parents, this led to a time of disorganisation and crisis where they needed rescue from family and possibly rescue by varying professionals. For other parents, after several months had passed, the sensation of being trapped in the dark and being isolated did ebb and the stormy time appeared to subside for now. Parents then felt more able to see those people around them that could help and there was an improvement on the darkness and loneliness. This is represented in the sandstorm as grains of sand that are beginning to fall away from the bottleneck.

Parents then move to the third area of the NGS, a safer space away from the turmoil of falling and the bottleneck in the sandstorm, called 'On The Ground'. On the ground, at the bottom of the hourglass is a space that parents can journey in and out of day by day. The sandy ground may have steep inclines and easier to tread areas but also sinking sand to represent the daily difficulties of life grieving for their baby. Once on the ground there is an open exit but the sand at the bottom represents their ongoing emotions that some days they sink over their head into and other days they can walk on top of the sand, depending on their life triggers. When life triggers are

profound and grief pangs hit with strength, it is as if the sand timer has been turned over and parents may find themselves back at the falling in stage and into the sandstorm.

The NGS is conceptualised alongside established grief theory that is discussed in Chapter 7, therefore these three phases of the tool are not linear. Parents are likely to have significant grief triggers that may cause them to return to an earlier phase, or inversion, of the NGS with all the emotions and experiences associated with that phase.

6.9 Summary

The findings of this study have represented the collective parental narrative to reveal four superordinate themes of 'the enormity of grief', 'being isolated', 'trying to survive' and 'routes to an improved future'. Each superordinate theme had subordinate themes arising out of the topic. Data extracts have been utilised to support the thematic discussion with verbatim comments from parents. The NGS has been introduced as a visual conceptualisation of the collective narrative. Reflection points were used to provide insight into my thoughts and feelings, and conceptual development arising from the interviews, data analysis and interpretative processes.

Chapter 7 – Discussion

7.1 Introduction

This chapter presents a discussion related to the study findings presented in Chapter 6 and will draw on contemporary and seminal literature and national guidance as appropriate to contextualise and explain the findings. The superordinate themes will be critically evaluated. The 'Neonatal Grief Sandstorm' will then be explored in relation to visualising parents' experiences and explore the implication for clinical practice. First, the strengths and limitations of the study will be discussed.

7.2 Strengths and limitations of the study

The key strength of this study is that it is the first UK-based qualitative research, focused on parents' perceptions of their experiences of end of life and support after a neonatal death. The study empowered parents to have a voice in an context that is rarely explored due to the ethical challenges related to undertaking research in sensitive subjects (Currie et al, 2016). This study weaves the end of life experience to how parents navigate grief and draw on support, rather than researching these experiences as separate issues. The study findings have informed the development of a visual tool that has the potential to assist both professionals and parents in understanding the grief journey across their care trajectory.

The strength of the findings of this thesis are based on the in-depth data collected and detailed analysis of parents' narratives. However, the extent to which these findings are credible depends on the rigour in which the research was undertaken, presented in Chapter 5, Section 5.4, and the way my personal influences have been accounted for presented in Chapter 1, Section 1.1.

The key limitation of this study is the homogeneity of participants and a parent only focus, rather than including wider family experiences. Homogeneity can be a constraint across research methods. However, in IPA, homogeneity in the sample is central to the methodology aim and facilitates data that elicits a phenomenon of interest that is intimately known by the participants. The phenomenon of interest in this study is a little known or discussed experience and therefore, the participants are

a select, homogenous group. Ideally, participants would have been recruited from a range of ethnicities, but this was not possible as there was no available funding for translation and therefore the participant information leaflet requested participants who were fluent English speakers. As a result, all the participants were White British in ethnicity. This was an anticipated outcome of the funding limitations of the study and the possibility of recruiting English-speaking non-white British ethnicities was not realistic. Although all the participants were White British in ethnicity, they were from a diverse cross-section of social class covering four of the seven social classes according to the Great British Class Survey Experiment (Savage, Devine, Cunningham, Taylor, Li, Hjellbrekke, Le Roux, Friedman, Miles, 2013).

There was a potential limitation of homogeneity in terms of gender. Fathers are underrepresented in children's palliative care research, with the focus of research often being on mothers as the primary care giver. Further, fathers are known to be more difficult to recruit in healthcare research than mothers (Macdonald, Chilibeck, Affleck, Cadell, 2010). The recruitment strategy for this study was developed to address this potential limitation and study materials were developed to be inclusive of potential father participants as discussed in Chapter 5.1.2. In addition, interviews were offered at time when father may more likely to be available such as evenings or weekends. Although there was not equal representation of both mother and father voices, there was representation of different gender perspectives and experiences.

This study focused solely on parents' experience of neonatal end of life and grief. A perceived limitation might relate to the singular experience of parents as this study did not seek to represent the experiences of other close family members, who would also be affected by the baby's death, such as, grandparents and siblings. While there is a growing body of family research (Brooten, Youngblut, Roche, 2017; Kempson and Murdock, 2009), the study did not aim to seek the impact of the baby's death on the wider family. The benefit of a homogenous perspective of the phenomenon of interest enhanced the viability of IPA as the chosen study method, meaning that rich data had a sole focus of representing the parents' experience. A different methodological approach might have been needed if siblings and grandparents, and health professionals were included. Different data collection methods would have been needed with siblings, in what would have been a wider study with more participants. Therefore, the valuable perspectives and experiences of grandparents

and siblings during and after the death of a baby are appropriate for future research, building on the findings of this study.

The limitations of this study have been fully recognised throughout the research process from conception to completion. Future investigation is needed to explore a more diverse range of experiences and will be discussed in Chapter 8.

7.3 The enormity of grief

The findings from this study resonate with pre-existing literature from both a theoretical and evidential perspective. The enormity of grief is considered through the lens of existing knowledge relating to grief and attachment theories. The differing perspectives of fathers and mothers through their grief processes are considered and discussed in relation to the literature.

7.3.1 Parents' perspectives related to grief, attachment and loss theory

The participant narratives and their experiences resonate with many aspects of the theories postulated in Chapter 1 (Bowlby, 1998; Klass et al, 1996; Parkes and Prigerson, 2010; Stroebe and Schut, 1999). All parents described a vast and deep experience of grief. Many perceived a dark, bottomless and unexpected experience day by day. There have been multiple perspectives and paradigms on conceptualising the initial experience of the death of a loved one and of being plunged into an encounter with grief, as discussed in Chapter 1.3.2 (Bowlby, 1980; Freud, 1954; Klass et al, 1996; Kubler-Ross, 1969; Stroebe and Schut, 1999). For example, Klass et al (1996) explored the concept of the grief experience and considered whether it was a case of broken hearts or broken bonds. For parents in this study, their grief centred on both but it was the suddenness and for some, the unexpectedness of having a 'broken heart' that was overwhelming. When a 'broken heart' is discussed in lay terms, society rationalises this in relation to an expectation of mending the 'broken heart'. The death of a baby is not an experience or hurt that can be mended, however it is a hurt that can possibly be modified only by certain factors. For example, in this study parents' accounts revealed a need to continue their bonds with their deceased baby, which potentially was their way of softening the pain of a broken heart to some degree.

The modernist approach to grief is a goal and solution-focused paradigm, where grief has an emotional intensity but there is an anticipated return to normal functionality with expedience (Klass et al, 1996). This societal expectation of a speedy solution to the grief and then life normalisation does not reflect the experiences of parents in this study who had a need to retain ties with their deceased baby for the rest of their own lives. In a modernist sense, continuing ties with the deceased and accepting life with a broken heart would indicate symptoms of emotional and mental illness (Kofod, 2015). All parents perceived themselves to be at the mercy of societal expectations of their grief expressions and this had a negative effect on their ability to be out in society with a perceived dysfunction. Klass et al (1996) identified the unsuitability of contemporary societal approaches to grief and suggested a fresh approach of multiplicity, where a rich texture of cultural possibilities around grief is accepted and which could be characterised as a post-modernist approach. This suggestion of acceptance and working alongside a varied and richly textured experience, resonates with the grief experiences of the parents in this study. Findings from this study highlighted that a change in societal expectations of parents' grief, emotions and behaviours, might have facilitated socialisation. It was not helpful for bereaved parents in this study to feel they must have a finite time for their grief, nor was it helpful for parents to feel that they have to sign up for a lifetime of intense grief. Societal expectations or preconceptions are unhelpful and potentially damaging. However, long-term grief for parents bereaved in the neonatal period is a realistic outcome (Klass et al, 1996).

The paradigm that best describes the experience or course of grief for a bereaved parent that fits with the findings of this study is Klass et al's theory (1996). They suggest that the course of grief is reflected in four distinct but intertwined areas: newly bereaved, into their grief, well along in their grief and resolved as much as it can be. The participants in this study were all in the 'into their grief' stage and 'well along in their grief' areas; none of the parents were newly bereaved, nor did they convey that their grief was resolved or would be resolved. Klass et al (1996) proposed that certain bonds facilitate and maintain connection with the lost loved one. The seminal research undertaken about the bonds and connections of 70 families with 125 bereaved children was undertaken in the United States, using qualitative methods (Silverman and Worden, 1992). Findings suggested that bereaved children use strategies for connecting with their deceased loved one in five

areas: locating the deceased, experiencing the deceased, reaching out to the deceased, remembering (waking memories) and linking objects. Further, Klass et al (1996) suggested that these bonds are as powerful and facilitative for adults who are grieving. The patterns of connection that parents were naturally drawn to mirrored the types of connection theorised by Klass et al (1996) and Silverman and Worden (1992). Parents instinctively patterned their coping behaviour including locating, experiencing, reaching out, memory making and linking objects of their loved ones. It is particularly poignant that parents in the context of NICU had a limited collection of tangible linking objects relating to their baby because of their baby's short life. Whereas, parents who have experienced the death of an older child will have many more 'linking objects'. Studies included in the literature review in Chapter 2, Section 2.6.2 support parents' experience of needing linking objects. Parents described the value of memory making at the time of death as well as having the mementoes after death (Baughcum et al, 2017; Kavanaugh and Herschberger, 2005). A range of examples from parents of how they remained connected in the present to their baby, are outlined in Chapter 6, Sections 6.6.1 and 6.6.2.

An alternate yet complimentary theory presented in Chapter 1, Section 1.3.4 that has resonance with the study findings presented in Chapter 7, was Stroebe and Schut's Dual Processing Model of Grief (1999). This model theorises patterns of grief and suggests people respond in two ways: loss-orientation and restoration-orientation (Figure 1.1, Chapter 1, Section 1.1.4). The model was developed initially from a review of grief theories (Stroebe and Schut, 1999) and from findings from their empirical studies and they suggested that oscillating between the two directions of loss or restoration is likely to result in the healthiest pattern of grief (Stroebe, 1992; Stroebe 1998; Stroebe and Schut 1998). Most of the parents in this study appeared to reflect a loss-orientated position, where the grief intruded daily, they were isolated from some family members, social groups and reluctant to engage in looking at the future. However, some parents appeared to be to some extent in the restoration-orientated position, and perceived hope for their future, sought distraction through work and other activities, and tried to avoid remembering the events of their babies' death. Nevertheless, parents that appeared to be in the restoration-orientated position did have times and days where they still perceived themselves to be immersed in the grief work, with a distinct mood change, intruding sadness and a sense of inertia. This indicated that the restoration-orientated parents were still very

much moving between the two directions of grief, in a healthy way (Stroebe and Schut, 1999).

It is pertinent to return to the theories of attachment introduced in Chapter 1, Section 1.4.1 and consider them in the light of the experience of parents who had made strong attachments to their baby but had now experienced the loss of that attachment. Studies about the bonds between parents and their baby have tended to focus on the maternal-baby physiological and instinctual adaptations that take place after birth (Klaus, 1998; Klaus and Kennell, 1976). Whilst the focus is primarily on the mother, these studies found that the early bond between mother and baby is strong soon after birth. Further, it is asserted that the death of a baby in the neonatal period prompts a pattern of response akin to the loss of attachment of someone who is widowed (Klaus and Kennell, 1976). They further asserted that parents in this situation should be offered 'counselling appointments' the day after death and a few days later. The impact of the loss of attachment to a spouse appears to support the depth of grief that parents in this study described, represented as the 'falling in' of the NGS (Figure 6.2), as the bond with their baby was severed. Bowlby (1998) reflected in his discussion of Klaus and Kennell's work, that the way procedures around the death are managed could intensify the emotional difficulties that parents experience. Whilst significant advances have been made in neonatal end of life care over the last decade, it is poignant that the parents in this study were deeply affected by how care was navigated by professionals during this time period.

Parents described the act of leaving their baby in the NICU after death as one of the most difficult things they had to do. This act of severing the final bond between themselves and their baby stayed with parents and appeared to have a later effect on their identity as a parent. Bowlby (1998) emphasised that the experience of neonatal death affects the affectional bond. The affectional bond is centred on one person (parent to baby) and it is a persistent bond. Proximity to the baby is crucial to the development of the affectional bond, driving the instinct that mothers have to stay close to their baby, with any involuntary separation causing distress (Bowlby, 1998). Parents in this study described their distress at separation from their baby not only as an immediate unbearable event but also as a persistent emotion. Parents' had an overwhelming desire to be close to their baby in the NICU and the period after death. This experience was also identified by several studies in the literature review in

Chapter 2 (Abrahams and Hendricks, 2017; Armentrout, 2007; Baughcum et al, 2017; Brosig, 2004; Currie et al, 2016). Further similarities were noted related to parents' continuing bonds with their baby assisting their ability to deal with the physical separation both in this doctoral study and identified in Armentrout's (2007) study.

The shape of parents' grief, their attachment and loss behaviours and coping mechanisms have strong resonance to the theories outlined in Chapter 1, in particular, those of Bowlby (1998), Klass et al (1996) and Stroebe and Schut (1999). Parents' natural instincts to remain close to their baby and the continuation of the affectional bond. However, the depth and vast emptiness of their experiences, and the different ways that parents described their grief journey, meant that no particular theory explained their experiences in entirety.

7.3.2 Uncertainty

'The enormity of parents' grief' was intensified by the uncertain and precariousness of their baby's life; uncertainty was a thread across parents' narratives, particularly during the end of life phase. The concept of uncertainty in healthcare has been widely studied in the last 20 years with an evolving understanding of its impact on patients and their families' experiences (Morse and Penrod, 1999; Penrod, 2001; Penrod, 2007). Uncertainty following a threat to health occurs when the individual is unsure about the best course of action (Morse and Penrod, 1999; Penrod, 2007). The individual may know what outcome they want to achieve but are unsure how or whether they can to get where they want to be (Morse and Penrod, 1999). Parents' had an overwhelming desire was for their baby to recover, but they were powerless to help, and struggled to navigate through their experiences. At times, interactions with health professionals added to parents uncertainty about their baby's condition and prognosis. Morse and Penrod (1999) highlighted that uncertainty paralyses hope, and that the individual merely exists in an emotional state. While parents described existing in a state of emotion, their feelings of uncertainty were characterised as lurching between hope and despair because of the vague information given to them.

A concept analysis of uncertainty refined and expanded earlier definitions resulting in uncertainty being described as "a dynamic state in which there is a perception of

being unable to assign probabilities for outcomes that prompts a discomforting, uneasy sensation” (Penrod, 2001, p.241). The characterisation of uncertainty as a dynamic state, mirrored parents’ narratives and evoked a range of emotion and feelings including anxiety, confusion, doubt and blame. Uncertainty was compounded by parents being in an unfamiliar, overpowering and alien environment; they had no previous or similar experiences to draw on. Parents struggled to think in a way that would help them deliberate on the probabilities of the events that were unfolding and their ability to make decisions was impaired by lack of knowledge. Uncertainty can become overwhelming when the individual perceives they have no control over events and lack confidence in managing the situation (Penrod, 2001; Penrod, 2007), which reflects the situation of parents who participated in the study.

Removing or reducing uncertainty involves using strategies to gain control and develop confidence in managing the situation causing the uncertainty (Mishel 1988; Penrod 2002). After their baby’s death, uncertainty remained a dominant feature of parents’ accounts. There was ongoing reflection about whether they or health professionals could have done anything differently to secure a different outcome. Penrod (2007) postulates that uncertainty can be contemporaneous, existing in the past and present and that a sense of control and confidence in choosing variable probabilities of outcome are factors that can be relived. Parents in this study felt out of control in the NICU situation and they had little confidence or empowerment in their parenting role alongside minimal knowledge or understanding of their baby’s condition, care and medical interventions. Parents’ uncertainty began from the experiences they encountered during palliative and end of life care and resurfaced during their grief journey. Parents in this study were still unravelling their feelings about their uncertainty up to two years after the bereavement. Findings from this study contrasted with Abrahams et al (2017), identified in Chapter 2. Abrahams et al (2017) described parents’ experiences of uncertainty about their parenting role for a sick baby, the wish to do normal things with their baby such as, feeding, changing and holding them was present but they felt uncertain about what they could and could not do. Parents’ uncertainty did not appear to continue when their baby encountered the end of life phase (Abrahams et al, 2017). In contrast, parents in this study experienced feelings of uncertainty related to diagnosis, prognosis, hope and hopelessness.

7.3.3 Differing gender experiences

Parent descriptions of the enormity of grief highlighted some differences between genders. The differences between male and female grief are often culturally postulated in a dismissive way with stereotypical behaviours suggested such as, the notion that women cry and men do not (Martin and Doka, 2000). However, gender differences have been studied and applied to the Dual Processing Model of bereavement in a spousal bereavement setting (Stroebe et al, 2001). This study suggested that men and women deal with spousal bereavement differently in terms of the effect on mental and physical health. There is suggestion that men lean towards a restoration-orientated experience and that women lean towards a loss-orientated experience. However, the phenomena explored in Stroebe et al's (2001) study is significantly different from the parents in this study and there are factors related to the death of a baby that are not identified in their research such as, parent to baby attachment and the lack of tangible memories. These differences in neonatal bereavement appeared to influence the pattern of grief found in this study. The tendency for gender associations with loss-orientation and restoration-orientation may be applicable in most situations, but do not reflect all contexts and situations. Fathers in this study were quickly back at work through necessity, experiencing the distractions of occupation, while mothers were on maternity leave with little to occupy their thoughts other than their baby and their own grief. These practical circumstances directed grief towards loss or restoration-orientation when at times, fathers wanted to be at home with their partner, focused on their baby and their grief. Some mothers also expressed that they would have welcomed something to do, to be occupied and distracted from their grief. In contrast to parents' experiences in this study, one study from the literature review in Chapter 2, highlighted fathers' experiences of having to go back to work during their baby's end of life period (Currie et al, 2016). Parents in this doctoral study were able to be together with their baby at most times through their baby's short life.

From the studies reported in Chapter 2, few compared the experiences of mothers alongside those of fathers. One study however, explored the differences between the levels of grief experienced by mothers and fathers following the death of a twin in the neonatal period (Swanson et al, 2009). Using a validated grief measurement tool, Swanson et al (2009) found statistical significance related to mothers' despair on the depression scale compared to fathers. In contrast, fathers' retrospective coping had

statistical significance compared to mothers which indicated that while mothers may have deeper and ongoing despair that fathers may be more deeply affected in other areas. It is difficult to compare Swanson et al's (2009) quantitative measures with the self-reported experiences from parents' own perspectives in this doctoral study, however, fathers' difficulty coping in Swanson's study resonates with fathers' experiences of profound grief in this study. Other relevant evidence is outside of the neonatal period and in the field of the death of a child (Carroll & Schaefer, 1994; Sidmore, 2000; Schwab, 2007). In Schwab's study, a key finding was that mothers expressed more hurt and depression and were unable to conceal their emotional responses such as crying. In contrast, fathers were as likely to experience social isolation and death anxiety. Comparing the findings of Schwab (2007) with the findings from the study presented in this thesis, whilst mothers had an intense, ongoing grief response and the emotional and somatic experiences that accompanied their grief, fathers also described what could be thought of as a deep and intense grief that lingered. However, their ability to express their emotional response was hindered by the lack of bereavement leave, responsibilities to work and a culturally-mandated sense that they must be seen to be coping.

From a societal perspective, there is a general belief that men should be the stronger individual when it comes to the loss of a loved one (Doka and Martin, 1999). Both fathers of this study spoke of the many practical and gruelling tasks that they undertook after their baby died, such as collecting birth certificates, going to the mortuary and registering the birth and death. Fathers wanted to save their partner from the heartache of these tasks but found the personal burden heavy. Findings from this study contrast with experiences identified in the literature review in Chapter 2. In Pector's (2004) study, parents described a hospital social worker who navigated and guided practical events after death. This was not desired by all parents but sought after by some. There is a cultural perception that tears and many other natural emotions of grieving, weaken masculinity and how men are perceived by others (Martin and Doka, 2000). Fathers in this study described the societal pressure they were under to be the strong one, but also perceived the need to be strong to support their partner. Nevertheless, fathers should not need permission to emote in any way that offers catharsis from the heavy and unrelenting psychological burden of the death of their baby. Further, the pressure exerted on fathers to be strong in the face of such an event, poses a risk to their mental health and well-being.

This study did not assess levels of grief with a validated tool as the aim was for parents to voice their own perceptions about their grief. Therefore, this study does not measure and compare the grief mothers and fathers experienced, the findings reflect parents' thoughts about their own grief, which have been compared to contemporary theory. The key message about gender differences that emerged from this study is that both fathers and mothers need to be assessed, cared for and supported on an individualised basis throughout their grief journey, rather than relying on preconceptions about how that person will grieve based on gender. Parents' perceptions of the enormity of grief have been considered alongside seminal and contemporary theories. The enormity of grief relates to the following discussions of 'being isolated' and 'trying to survive'.

7.4 Being Isolated

Isolation as a core part of the parents' narrative although not unexpected was not anticipated to be a superordinate theme, however it was a dominate feature of parents' narratives. The theory of isolation as a behaviour and isolation arising out of grief was not reviewed in Chapter 1. Understanding and exploring the findings in relation to isolation reported in Chapter 7 required reviewing existing theoretical perspectives on bereavement isolation. First, the concept of isolation from the perspective of thought ideation is discussed and second, isolation behaviours in grief experiences are discussed and applied to the findings.

The concept of isolation is defined as the creation of a mental gap between an ominous thought or feeling (Baumeister, Dale, Sommer, 1998). Freud's (1966) seminal work analysed ego defence mechanisms and isolation and offered examples of how a 'neurotic' might pause in conversation between thoughts, creating a gap, not allowing those thoughts to converge. Baumeister et al (1998) suggest this is a process of the individual minimising the impact of the troublesome thought or feeling, however it does not remove it altogether. As an initial concept, this representation of isolation is grounded in psychoanalytic theory applied to those with significant mental illness and appears to have only tentative links to parents narratives reported in this study.

Most of the theory of isolation that has evolved, relates to isolation as defensive ideation (Baumeister et al, 1998; Freud, 1966). Although not described across parents' accounts, one parent described how she moved away from thinking about the end of her baby's life, made a conscious effort not to think about it, and did not want to share the events of her baby's death during the interview. A purposeful push away from the events of her baby death was probably a protective action, described by Freud (1966) as a defence of ego through isolation, by removing herself from the emotional pain of the experience. She knew the thoughts and feelings were still there, but she did not want to think about or address them. In contrast, other parents' descriptions of isolation related to a sense of individual loneliness due to their bereavement or the experience of pulling away from or being removed from established social groups. Parents knew they were removing themselves from people as a protective and defensive measure, Chapter 6, Section 6.5. Parents rationalised self-isolation in term of avoiding being in a social situation with that individual or a group that was too difficult or emotionally painful.

Parkes (2009) consolidated his extensive work on loss in his book "Love and Loss", on which he draws conclusions from the synthesis of his individual studies. While these studies do not appear to have been published elsewhere, Parkes' novel approach to attachment and grief is helpful in linking isolation to grief theory at a conceptual level. Parkes (2009) identified that through the evaluation of grief-loneliness measurements, that adults living with another person did not positively affect a sense of loneliness however, living with someone was associated with lower levels of grief following a bereavement. Parents in this study were living with their partner and yet most described a sense of loneliness in relation to their individual emotions. Mothers and fathers' loneliness were derived from a need to protect their partner from the burden of their emotions, which led to the feeling of being alone in their grief. The experience of isolation and loneliness was reinforced by the perception that no one else could understand their suffering. Parents' experiences of isolation share similarities with studies from the literature review in Chapter 2 (Currie et al, 2016). Parents in Currie et al's study described isolating experiences from family, friends and sometimes their spouse. Mothers in this doctoral study experienced spousal isolation in terms of the physical reminders of pregnancy, labour and lactation that were still present when they returned home but they did not have their baby to love, feed or care for. Their partner could not share and therefore

understand what the experience of physical remnants of pregnancy and lactation were like for them, leaving mothers feeling alone.

Across parents' accounts, social isolation was described in depth (Chapter 6, Section 6.5.2). Socialisation through human relationships has the potential to ease some of the pain of grief. Stroebe and Schut (2001) reasoned that that social support from family, friends and the community can 'buffer' grief while for other people social support does not ease the pain. Parkes (2009) cautions against the assumption that a lack of social support means a lack of buffering of the pain and believed there was a connection between social support and isolation and attachments. He suggested from that different kinds of attachments offer different support potentially easing the sense of social isolation. For example, children may be perceived as not being able to offer support to someone who is bereaved yet can ease the sense of isolation by way of distraction and through their own social communities. Further, other attachments such as having to care for a pet can offer support, ease the sense of isolation and give a sense of purpose. This resonates with one account in this study, where a mother described in depth the importance of her dog in her life and her devastation by the loss of him, as he had been her companion in the day when all the family was out at school and work.

Parkes (2009) studied a sample of bereaved adults using an 'end of tether' score, measuring who they turned to when they were at the end of their ability to cope. The findings concluded that 60% and 48% of the bereaved participants would not seek support from their family or friends respectively. The concept of confiding relationships was however found to be significant in grief and loneliness. All parents in this study reported having someone who they confided in, either their partner or mother. Some parents had a friend who had experienced a similar bereavement and this was a valued confidence. Confiding relationships appear to have significance in the context of loneliness and can alleviate the experience of loneliness in some situations.

Parents' experiences of being alone and isolated in their grief and emotions are supported by seminal and contemporary evidence. Being alone and isolated links intrinsically with the enormity of grief presented in Section 7.3.

7.5 Trying to Survive

The experience of 'trying to survive' spanned from the end of their baby's life and was still prominent at the time parents were interviewed. Parents' narratives were often dominated by their need to survive after their baby's death and trying to cope with the events they had experienced during end of life. Parents had a need to reinforce their own identity as a parent and the continuance of their baby's identity; talking about their baby provided catharsis and comfort. Parents leaned on their loved ones and sought professional support to survive the overwhelming nature of grief. This section considers the issues of identity, talking about their baby and support strategies, drawing on contemporary evidence.

7.5.1 Parents' identity and role

Parents' identity and diminishment of their parenting role at the end of life was prevalent across each narrative. A diminishment of their parenting role was not unique to first-time parents and those that had other children still sought to affirm their parenthood of their deceased baby. Parents' role appeared to be threatened both at end of life and after their baby's death. Most parents in NICU experience a crisis over their role and identity even when their baby is not dying but this may be emphasised when the baby dies (Huenink, Porterfield, Dowling, Thibeau, 2017).

Understanding why parents experience this crisis of identity is important to understanding the enormity of their grief. Dias, Docherty, Brandon (2017) investigated the challenges facing bereaved parents in the first six months post-bereavement through a descriptive qualitative study design. Mothers and fathers were included in this study and one of the themes relevant to this section is parent-identity conflict. The study found that the mere absence of a child prompts an identity crisis, which identifies with the findings of this study presented in Chapter 6, Section 6.4.4. A meta-synthesis of parent experiences in the PICU also identified the importance of loss of parent identity within the main theme 'reclaiming parenthood' (Butler, Hall, Willetts, Copnell, 2015). Parents' experiences in PICU are similar to those of parents in NICU and so it is reasonable to consider transferability. The parenting role was found to be threatened by a disempowerment at end of life that extended into life after the death.

Further, findings from this doctoral study have similarities to a study by Abrahams and Hendricks (2017) reviewed in Chapter 2. Their study set in the NICU, identified two phases of parenthood: assigned parenthood occurring at the birth of their baby and distant parenthood, that which occurs as their baby is dying and their experience after death. This resonates with some of the parents' narrative in this study where their babies were completely covered in tubes and monitoring equipment. In addition, sick babies are particularly sensitive to movement so there was little parents could do for their baby but watch. This was frustrating and sad for parents and they felt superfluous, unable to provide anything that their baby needed and their identity as parents faded. The similarities between these two studies reveal and reinforce that for some, the identity of a parent is threatened by the impending and actual death of their baby.

The end of life is potentially a time where nurses lose sight of the underpinning philosophy of family centred care. This period in the NICU is often fast-paced rather than peaceful and invasive treatment and life support is ongoing. It can be difficult for nurses to find time to empower parents when they prioritise the physical care needs of the baby above the psychological support of the parents. Epstein (2010) found from their study with multi-disciplinary professionals involved in a NICU at the end of life, that parenting options were considered an obligation rather than an essential component of care. Parenting options at the end of life may be related to time pressures but there was limited discussion of this in Epstein's (2010) study. Nurse and Price (2017) undertook an exploratory study of junior nurses who were undertaking a qualification in the speciality of neonatal care, considering their experiences of end of life care. Participants rated 'involving the family appropriately' as a high challenge when caring for babies in the NICU setting which were related to three areas: lack of knowledge, experience and competence. Parents in this doctoral study reported that experienced nurses were often allocated to care for them and their baby, but they still encountered disempowerment in their role as parents, suggesting experienced nurses might also find empowering parents at the end of life as a challenge. Similarly, Currie et al (2017) a study included in Chapter 2, explored parents experiences of end of life through a descriptive qualitative study and identified that there were periods of increased and decreased involvement of parenting in this phase. The narratives of the participants in the study undertaken as part of this thesis described parenting roles coming to the fore again after death

when they were able to spend time with their baby. Communication conflicts and a lack of compassion alongside issues of travelling long distances to see their baby were also identified as affecting the parenting role in Currie et al's (2017) study. These experiences resonate with the parents' narratives in the findings of this study, presented in Chapter 6.

Parents' described questioning their parental identity throughout their grief journey, asking themselves if they were really a parent to their deceased baby. They described how they repeatedly affirmed to people around them that they were a 'mum' or a 'dad' to their baby. All parents described their deceased baby as being one of their family and never left their baby out of family descriptions. Parents used these self-affirmations of their identity to cope with their doubt and role conflict. Parents found it empowering and comforting to assert their identity to friends, family and those who did not know their baby's life and death. This appeared to be a strategy for resilience to survive the grief experience.

7.5.2 The identity of their baby and the need to talk

Parents wanted their baby to be known as an individual and for their identity to live on. This is an inherently difficult experience for parents bereaved during the neonatal period as many people in their lives will not have met or seen their baby and the proof of their baby's existence is minimal. This experience reveals why so many parents feel disenfranchised in their grief because it is difficult for society and their social world to comprehend. Parents perceived that their baby had barely left a trace of their life behind. Two studies from the literature review in Chapter 2 identified similar themes about parents' need to talk about their baby after death (Armentrout, 2007; Brosig, 2007). Parents in these studies described talking about their baby as the most helpful activity in their grief (Armentrout, 2007) and being able to talk to a trusted person about their baby as a coping strategy and to keep the baby's memory alive (Brosig, 2007). In this doctoral study, the parents' need to talk and reinforce their baby's identity was clearly associated with their approach to grief and their natural desire to maintain bonds with their baby; this section is therefore, related to the earlier discussion on enormity of grief.

Worden (2009) suggested that some bereaved parents may suppress facts and discussion about their loss, however this was not the case for any parents in this study. Parents' need to talk about their baby was powerful, persistent and purposeful.

Similarly, findings from Alam, Barrera, D'Agostino, Nicholas, Schneiderman's (2012) mixed methods longitudinal study identified that both mothers and fathers expressed the need to talk about their child, although this was more prevalent in mothers than fathers. These findings are cautiously considered because of the difference in context that the study was undertaken, that is, bereavement after the death of a child due to cancer. Parents in this study spoke about the need to talk, although there did appear to be more emphasis on this for mothers. This could relate to the time that mothers had to attend to grief work because they were still on maternity leave.

Coping behaviours in the form of sharing the pain with those in the person's social world have been identified (Klass, 1996). This was the experience of parents in this study, sharing their experiences eased the emotional weight in their minds and hearts when they were able to talk about their baby. Conversely, as described by one parent in this study, talking about her baby in depth, had the opposite effect of a difficult emotional burden for days afterward, yet the need to talk was still persistent. Nevertheless, telling the story of their baby was a core part of parent's coping behaviour. Bosstico and Thompson (2005) suggest that story telling is part of parents' sense-making of their experiences. For parents to be able to explain what happened, they need build a structure and understanding that normally includes reflection on events. In addition, there is a body of literature that suggests that talking about the loss, potentially reduces isolation and loneliness, demonstrating how inter-linked the themes of this study are (Gilbert, 1989; Feezel and Shepherd, 1987).

Parents' need to talk was evident in their narratives but also clear in their eagerness to talk to me in the research interview. Parents did encounter barriers with the need to talk at times because finding someone willing to listen was not always easy. Talking about their baby coincided often with being supported by another person which will be discussed in the following section.

7.5.3 Coping with support from others

Parents needed the support from different individuals and organisations at differing junctures in their grief journey. Their partner, family and friends had the potential to be available any time of the day, this contrasted with professionals and peer support groups whose availability was often limited. Support from loved ones was a core element to surviving the first year of grief and beyond for parents in this study. Most

parents were able to talk to their partner, who had shared the birth and death with them. Several studies in the literature review, Chapter 2, identified partner, family and friend support as vital to their ability to cope with grief (Abdel Razeq and Al-Gamal, 2018; Brosig, 2007; Currie et al, 2016). In contrast, one study from the literature review identified experiences where parents were not supported by their family, causing feelings of abandonment (Kavanaugh and Herschberger, 2005). Alam et al (2012) found that not all partners were supportive of one another and that in some instances, partners left one another to cope. This finding has similarities to a study from Chapter 2, literature review where it was identified that partners can withdraw from one another after their baby's death (Glaser et al, 2007) or even be abandoned by their partner (Kavanaugh and Herschberger, 2005). Parents in this doctoral study were all generally supported by and supportive of their partners but there was variability in the level of support offered and received.

Parents turned to family regardless of the level of partner support they had. Their own parents (maternal and paternal grandparents) were a source of reliable support for some. Roose and Blanford (2011) evaluated a family-orientated perinatal bereavement programme using survey data with parent and grandparent respondents. Parents' responses demonstrated that grandparent support was crucial for the whole family. However, grandparents were potentially more supportive in this situation because they had been able to access the support programme themselves. In the UK and for families of this study, grandparents rarely have access to support after a neonatal bereavement and yet, their support to parents of this study was vital.

Parents' narratives about support from friends was a sensitive subject and each parent had a story to tell about being hurt by friends. Most parents had come to terms with leaving many of their previous friendships behind because they had been hurt by comments or avoidance. This resonates with the findings of a study in the literature review, Chapter 2, where parents described finding themselves in a social desert after their baby's death (Einaudi et al, 2010). Klass (1996) suggested that it is usual for parents to have to teach friends how to relate to them post-bereavement. One mother in this study described having to make her friends feel comfortable in conversation by bringing up her baby to show them that she could cope with conversing about it. In addition, Klass explained that it might be necessary for

parents to caution friends and family not to offer advice but to listen and just be alongside them (Klass, 1996).

One of the most valuable support strategies that appeared to be crucial to parents' survival was peer support either through friendships or facilitated bereavement groups. Bereavement support groups such as SANDS were often the conduit through which new personal friendships with a peer were made. Klass (1996) explored bereaved parents' experiences through a 'compassionate friends' group and narratives indicated that the only people able to understand them were those with the same experiences, similarly bereaved parents. Umphrey and Cacciatore (2011) undertook a study observing a parental bereavement support group for parents after a child's death over a five-month period. The findings conveyed the central narrative themes within group discussions as being the death story, coping and connecting with others. These themes resonate with parents from this study that attended peer support groups. They may have utilised the group to direct their need to talk about their baby and reinforce their baby's identity as discussed in the previous sub-sections, but the group facilitated their connections with other bereaved parents. This format of support reminded parents that they were not alone, that they were alongside people who had encountered similar difficult experiences. Peer support groups were not right for all parents in this study and this factor was also identified in two studies from the literature review where parents knew about peer support groups but did not wish to go (Kavanaugh and Herschberger, 2005; Pector, 2004).

All parents described their need for professional support at some point post-bereavement. Most parents accessed support from a bereavement nurse and/or a counsellor. There is a paucity of UK or international evidence about the role of the bereavement nurse and the effectiveness of involvement of bereavement nurses with families. The most relevant literature about bereavement programs focuses on description or literature review of care at the end of life or relates to nurses' perspectives of delivering end of life care (Gibson, Finney, Boilanger, 2011; Harvey, Snowdon, Elbourne, 2008; Rondinelli, Long, Seelinger, Crawford, Valdez, 2015). Soni, Vasudevan, English (2015) undertook a survey of NICUs in the UK and all the 29 NICU respondents considered that they offered bereavement support in the form of the consultant appointment. The study did not offer data about bereavement nurses. Similar findings are available from a longitudinal study over six years

undertaken on two UK tertiary NICUs where bereavement support is the six-week appointment (Banerjee, Kaur, Ramaiah, Roy, Aladangady, 2016). Neither of these studies offer tangible evidence for bereavement support. There is a lack of evidence about bereavement nurses in any setting, however, parents in this study that utilised the support found it valuable to the point they could not imagine how they would have survived without it. In addition, those parents who did not access this mode of support described knowing that the bereavement nurse was there was a comforting thought. Some studies from the literature review (Chapter 2) identified a similar need for a professional guide after the either death, a caseworker, social worker or hospital-based bereavement officer (Pector, 2004; Richards et al, 2015). However, a social worker was not desirable for some parents (Kavanaugh and Herschberger, 2005).

Reflection Point 7.1: contrasts in perceptions of bereavement support

Parents did not consider the six-week appointment with a consultant to be bereavement support. Those that attended, perceived the appointment was about information provision relating to the of cause of death and post-mortem results. Although parents described a compassionate communication approach to conveying the information, there was not a psychological supportive aim to the meeting. As a bereavement nurse, I was aware that some medical colleagues lacked insight into the potential support that could be offered at these appointments. This is not unique as some studies cited also highlight a lack of understanding that a follow-up appointment is part of bereavement support. It is possible that this appointment could be part of a range of supportive measures but alone, it offers little to support parents in their grief journeys.

Parents' journeys to accessing counselling services was problematic and parents were not offered any counselling when on the NICU. Most parents tried to access counselling after the death and emphasised the need for referral to an experienced bereavement counsellor rather than a general counsellor. A survey of NICU bereavement support in the UK found that 40% of the 29 respondents had a counsellor on the NICU, however it was not clear if counselling was offered to parents post-bereavement or during the NICU admission (Soni et al, 2011). Three approaches to initiating grief counselling have been identified (Worden, 2009). First, grief counselling should be offered to all, especially if there is the death of a child or parent. The second approach acknowledges that some individuals will need support with their grief, but may wait until a difficulty is experienced which normally presents

as a crisis. The third approach is preventative by predicting, through assessment, who is likely to need interventions. Parents in this study all accessed counselling after experiencing a crisis of being unable to cope and some encountered a 'battle' for access to this mode of support. Parents voiced the need for an open and easier access to support and they perceived that a bereavement nurse would be able to refer them or detect a need for counselling before crisis was reached.

Parents clearly described the need for a range of support from loved ones and professionals. All parents sought some professional support in their grief journey. Access to support was difficult and at times and this was hard to cope with when they were in crisis. Routes to support need to be clearer and easier, some of these issues will be discussed in the next section.

7.6 Routes to an improved future

Parents were motivated to discuss prospective care directions and support services for bereaved parents of the future. Parents often approached this by offering poor examples of care or support from their personal experiences to suggest alternative approaches or a direction of support they wished they had had. Most of the examples parents described were routed in the end of life phase of care. Their recommendations focused on three key areas: communicating clearly and with care, reframing the NICU and mapping appropriate support. This theme describes and interprets discussion about routes to an improved future, giving credence to the issues at end of life raised by parents.

7.6.1 Obstacles to high quality end of life care

Although parents' narratives about end of life care focused on a range of areas, they frequently returned to the experiences that had caused the greatest emotional turmoil or trauma during their grief journey to date. Most of these experiences that parents described could have been improved with minimal changes to care. Discussion about obstacles to high quality end of life are closely linked to the 'Falling In' area of the NGS.

The three areas parents' narratives focused on were: consistency of and continuity of care, communication between professionals and to parents and resuscitation

discussions. What is significant about all three areas is that a robust evidence base exists, national and best-practice guidelines are available for all these areas (Armentrout and Cates, 2011; DH, 2008a; DH, 2009; Hall, Cross, Selix, Patterson, Segre, Chuffo-Siewert, Geller, Martin, 2015; Janvier, Barrington, Farlow, 2014; National Care Bereavement Pathway, 2018; Together for Short Lives, 2017). Further, quality targets in these areas of care are known widely within the professions involved in neonatal care (BLISS, 2009; BLISS, 2010; British Association of Perinatal Medicine [BAPM], 2010a). Not all the guidance cited was available at the time of the study, however sufficient guidance was in place to support high quality end of life care. Nevertheless, parents described adverse experiences at end of life that impact negatively on their grief work.

7.6.1.1. Consistency of care

Most of the parents' narratives presented a picture of inconsistency of staff caring for their baby at the end of life. At this point in the care journey, parents were 'Falling In' to the NGS and it was a time of psychological distress, cognitive disorganisation and emotional dysfunction. The experience of inconsistency of care staff was distressing to them for three reasons: safety, mixed communication leading to difficulty with decision-making and having to repeat history and information to unfamiliar staff especially on the day of death. In the research interviews, parents were clear that they perceived that the quality of care both clinically and psychologically would have been improved if the care was delivered by a consistent team of professionals who had cared for them before and knew their baby.

Similarities to this study were identified in a study from the literature review in Chapter 2. Richards et al (2015) identified themes relating to problems with continuity of information and continuity of staffing and trust. This was also a UK study, which revealed a national picture of parents' similar experiences. Epstein, Miles, Rovnyak, Baernholdt (2013) explored continuity in the NICU and identified three interlinked issues, chronological continuity, relational continuity and informational continuity. Chronological continuity related to the number of nurses caring for a baby over time and was considered by parents as the key to how they felt about relational continuity (the ongoing relationship of the nurse to parent) and informational continuity (consistency and transfer of information) (Epstein et al, 2013). The contemporary economic climate within the NHS and its impact on staffing levels may be a factor in

having dedicated caring teams around the dying baby and family. Other organisational challenges include large, tertiary and level three neonatal units with considerable numbers of staff could result in parents not having a consistent person or named professional responsible for their care impacting on the continuity of care. However, parents' accounts in this study suggests health professionals may have a knowledge deficit about the importance of continuity of care for babies and parents and the potential impact it can have on quality of care. Spruill and Heaton (2015) undertook a study about a pilot implementation of a continuity of care model on a NICU. Education and organisation of care were core elements of the programme and results identified improved continuity and satisfaction for nurses and parents.

The national UK standards for staffing levels suggest that the nursing care ratio on day of death should be one-to-one by a neonatal nurse qualified in speciality (QIS) (BAPM, 2010b). There is no prescribed doctor ratio to baby beyond the expertise level and number of doctors allocated to the NICU according to the level of unit. Palliative and end of life care is not mentioned in the BAPM standards with regards to medical staffing. There is need for BAPM to guide strategic and organisational leaders further than staffing ratios and direct resourcing towards quality end of life care by providing continuity of care in the multi-disciplinary team around the baby and parents.

There are organisational benefits to ensuring continuity of care is resourced appropriately including a positive effect on the health and wellbeing of professionals, satisfaction and retention of staff (Spruill and Heaton, 2015). Moral distress in NICU has been identified as a concern for health professionals working in this environment because recurring ethical dilemmas and the pressures associated with high levels of palliative and end of life care and financial care constraints (Cavaliere, Daly, Dowling, Montgomery, 2010). Nurses working in NICU are at higher risk of moral distress than other professionals in the NICU because of nurses' consistent presence at the bedside and supporting parents during emotive and stressful care, and limited power in decision-making processes, which are usually within the doctor's domain (Epstein et al, 2013). The issue of moral distress on the NICU has been investigated from different perspectives and using a range of methods such as a survey of nurses with a validated tool, comparison of moral distress tools and systematic reviews of the literature (Cavaliere et al, 2010; Hamric, 2012; Prentice, Janvier, Gillam, Davis,

2016). Moral distress can lead to job dissatisfaction, high rates of absenteeism and a desire to leave the job (Prentice et al, 2016). Continuity of care at the end of life has the potential to improve satisfaction with care and for professionals to feel empowered in the care that they provide. Continuity of care can be promoted and facilitated by primary care giver models such as a named nurse, negotiated partnership approaches, nursing care delivery models and team nursing models which have wide successful implementation in a variety of clinical settings (Reis, Rempel, Scott, Brady-Fryer, Van Aerde, 2010; Spruill and Heaton, 2015).

The need for continuity of care at the end of life in the NICU has the potential to affect quality of care at the end of life and parents' grief journeys. Prioritising continuity of care across the medical and nursing professions at the end of life has the potential to improve care quality but also reduced moral distress in staff members, with positive benefits to staff health and wellbeing.

7.6.1.2 Communication in end of life care

Parents' narratives about the obstacles to high quality end of life care revealed some examples of poor or ineffective communication between parents and professionals. Poor communication was described across care including explaining the physiological condition and pathophysiological changes of their baby, discussions about deterioration in the baby's condition, end of life decisions, and withdrawal and withholding of treatment and choices at the end of life. Parents also focused particularly on communication in the context of resuscitation conversations, which will be discussed in Chapter 7, Section 7.6.1.3.

The experience that parents cited as most distressing was the experience of medical staff giving mixed information in the same day about hope for survival versus futility of treatment and certain death. This experience was similarly identified in one study from the literature review in Chapter 2 (Richards et al, 2015). These parents described mixed information experiences to be very upsetting and anxiety provoking. Inaccurate written information also had the same effect. The parents in this doctoral study perceived that conflicts of information between medical staff was not something that should ever happen at the end of life and that it required a change to improve parents experiences in the future.

There are a range of standards, guidance and evidence that direct professional communication at the end of life (BLISS, 2010; DH, 2009; General Medical Council [GMC], 2014; Nuffield Council on Bioethics, 2006; NMC, 2018; Price, McNeilly, Surgenor, 2006; Together for Short Lives, 2017; Xafis, Wilkinson, Sullivan, 2015). Outside of the NICU setting there are a range of communication models and frameworks that professionals can use to share difficult information or hold a conversation about psychological need that has arisen from bad news (Baile, Buckman, Lenzi, Glober, Beale, Kudelka, 2000; Griffiths, Wilson, Ewing, Connolly, Grande, 2015; Rabow and McPhee, 2000). However, the overriding issue is the availability of training for health professionals to undertake these conversations effectively and compassionately. Coad, Smith, Pontin, Gibson (2018) evaluated perceptions of health professionals working in children's oncology of an advanced communication programme. Findings indicated that knowledge of communication theories and strategies were enhanced, and simulation scenarios were valued training approaches. Training professionals for palliative and end of life conversations is not a linear process and Coad et al (2018) identified the need for post-course development after communication training. Effective training should start in undergraduate health professional curricula and continue into the clinical setting as part of ongoing professional development. However, whilst professionals on a NICU might possess the knowledge, skills and attitudes for discussing end of life issues, training is often not available or focused in the setting.

Contemporary training methods have the potential to inform and facilitate learners to practice the skills of advanced communication in any end of life setting relevant to the professional. Low to high fidelity simulation is the optimum approach to deliver training for this purpose. Simulation can be used to train either similar professionals or multi-disciplinary clinical teams together (Randall, Garbutt, Barnard, 2018). Some undergraduate curricula have now incorporated end of life simulation training amongst their methods to teach communication skills into their programmes for nursing, however, this is not widespread nationally (Mancini, Kelly, Bluebond-Langner, 2013). A range of teaching methods to meet diverse learning styles is useful however, role-play or rehearsal in some format is essential to capture the learning and to ensure learners have a chance to practice the skills in a safe environment (Randall et al, 2018). There are other role-play orientated training methods such as the advanced communication skills training originally developed for

the oncology setting which has been widely cascaded across the UK in a variety of settings. However, it is suggested that this method of training isn't suitable for all individuals and that medical professionals are resistant to mandatory communication training whereas nursing professionals are not (Turner, Payne, O'Brien, 2011). There are clearly obstacles to securing suitable guaranteed training for medical and nursing professionals in end of life conversations. Furthermore, training does not assure professionals' competency once they are trained, however, professionals are more likely to be confident and competent once they have been trained (Baile et al, 2000; Griffiths et al, 2015).

Clearer communication channels need to be prioritised with regards to mixed and opposite information between medical professionals. There are several tools available to facilitate clear, concise and informative reports such as SBAR: situation, background, assessment, recommendation (Blom, Petersson, Hagell, Westergren, 2015; Institute for Healthcare Improvement, 2015). Other adapted tools have been utilised for medical handover such as ISBAR: identity of patient, situation, background, assessment and action, response and rationale (Thompson, Collett, Langbart, Purcell, Boyd, Yuminaga, Ossolinski, Susanto, McCormack, 2011). The guidance and culture within NICU and the fundamental need to share information effectively between medical professionals requires prompt change and enhancement in line with recommendations (GMC, 2014; Nuffield Council on Bioethics, 2006; NMC, 2018). This change has the potential to affect communication with parents at the end of life in a positive way, resulting in parental grief work that is facilitated by the communication practices they have experienced, rather than negative reflections on communication intruding into parents' grief.

7.6.1.3 Resuscitation discussions

When a decision about palliation or certainty about end of life has been reached and agreed, a timely conversation about resuscitation and the patient's best interest needs to take place (GMC, 2010). The need to have a discussion related to resuscitation with the patient or next of kin is mandatory; the medical professional making the decision must discuss the decision with the patient or parent (Etheridge and Gatland, 2015). This has been tested in the Court of Appeal in *Tracey R v Cambridge University Hospitals NHS Foundation Trust & Ors* (2014) where a DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) decision was made and

documented without discussion or the patient's knowledge. The Court of Appeal judgement concluded that, "*there is a duty to consult a patient in relation to DNACPR unless the clinician thinks that consultation is likely to cause physical or psychological harm to the patient; this is more than just causing distress*" (Tracey R v Cambridge University Hospitals NHS Foundation Trust & Ors, 2014). However, for most of the parents interviewed for this study, these conversations were taking place, but the way in which the conversations happened, and the timing of the discussions caused significant distress. The impact of these conversations on parents in planning at the end of life, parents' expectations of resuscitation success and the consequent impact on grief experiences, impact on parents' grief. A clear framework and timeline for conversations related to DNACPR needs to be a priority end of life for care improvements in NICU settings. The ability to discuss resuscitation with parents requires the advanced communication skills discussed in the previous section.

Parents who are asked to discuss resuscitation decisions were those whose baby's treatment was futile, and end of life was either imminent or expected to be shortly occurring. Parents in this scenario are in the 'Falling In' section of the NGS with all the complications related to cognitive and emotional fracture and dysfunction as previously discussed. Although resuscitation conversations were not discussed in any depth in the studies from the literature review in Chapter 2, some studies identified the difficulties with decision-making, which included resuscitation (Brosig, 2004; Einaudi et al, 2010). Einaudi et al (2010) identified that parents did not understand what was happening and felt unable to express their views regarding these decisions and Brosig (2004) identified conflict that occurred around resuscitation conversations. In this doctoral study, after the death of their baby, parents have struggled with and reflected on the quality of these conversations in their grief work and their memories have been difficult and sometimes traumatic.

There has been shift in the language used when referring to DNACPR decisions both inter-professionally and when discussions are undertaken with patient and/or family. 'Do Not Attempt Cardiopulmonary Resuscitation' or 'Allow Natural Death' are suggested as an improvement on how professionals understand the decision-making options and may also offer more clarity to parents (GMC, 2010). 'Allow natural death' conveys an inevitable outcome and a natural eventuality. However, this language change does not appear to have been translated to the conversations that are being

undertaken on the NICU. Health professionals involved in initiating discussion about resuscitation should use the communication frameworks discussed in Section 7.6.1.2 to aid their discussion with parents. These frameworks facilitate conversation that is empathetic, that prioritises listening and addresses arising emotions as well as the essential information giving. However, several parents in this study had poor experiences where there was no coherent plan of conversation.

The challenge for change in this situation is to move clinical practice about 'DNACPR and Allow Natural Death' discussions to a position of known and secure process, where parents have positive experiences of a very difficult conversation subject. There are two suggested options: through the skilled and consistent use of Neonatal Advanced Care Planning (nACP) and/or by applying a stringent process nationally for the management of resuscitation conversations. These two options will be discussed in turn. Advance Care Planning (ACP) is a process that begins at palliative diagnosis and continues to death and beyond. It is a collaborative process that documents the decisions, wishes and choices that the patient (parents) along with health professionals might make in anticipation of the future, deterioration and death (National Council for Palliative Care [NCPC], 2008). ACP and transparent resuscitation discussions are a fundamental part of quality care (DH, 2008b). Within most ACP documents, there is a DNACPR or Management of Cardiopulmonary Arrest document. Resuscitation discussions should happen before death is imminent, ideally when palliation is agreed. ACP is widely used in children's palliative care across the UK, with a standardised Children and Young People's ACP (CYPACP) in use nationally. At present, nACP is not a prevalent form of care planning in UK NICUs and there is a paucity of evidence about its application to the neonatal context. However, from the national application of CYPACP in the UK, there is relevance of purpose in neonatal settings. This is an area that needs development with a national working party where organisations such as BAPM or Together for Short Lives would be the obvious facilitators of such a project, alongside PPI.

The second suggestion for improving resuscitation conversations is for a national implementation of a process similar to the robust processes that surround obtaining consent from families for organ donation. Resuscitation conversations take place in a similar emotional and end of life situation as organ donation and is therefore appropriately placed to influence development. There are some key elements of the

organ donation processes that have applicability to the context of resuscitation conversations (United Kingdom Donation Ethics Committee/Academy of Medical Royal Colleges, 2016). Whilst it is recognised that these two decisions differ because consent is not needed from the family for DNACPR, only discussion, the similarity in context suggests they have shared components.

Three key elements can be applied from organ donation to DNACPR discussions. First, mimicking the organ donation process, an Advanced Neonatal Nurse Practitioner (ANNP) or palliative/bereavement nurse with advanced communication skills could lead and facilitate the conversation. Second, the main information is conveyed in a planned discussion with detail and dialogue. Third, discussions should aim to inform parents' collaboration in decision-making but they should also recognise and attend to the emotions of this sensitive topic and facilitate parents' questions. At present, ANNPs do not lead these discussions in NICU, however, there is a national move towards Advanced Nurse Practitioners in other areas beginning to take the lead in this context. Training programmes using high fidelity simulation have been developed and successfully implemented to facilitate this role development (Garbutt, Barnard, Gloster, 2018). It is practical and feasible for similar training to be adapted for a neonatal scenario with ANNPs to equip them with the knowledge, skills and attitudes to be able to undertake this role competently.

Adapting and learning from the organ donation processes to apply to resuscitation conversations has the potential to positively influence parents' experiences of these difficult conversations. Parents who are involved in timely discussion, who feel informed about the reality and futility of resuscitation and are collaborators in decision-making will potentially feel less distressed in their grief work about this issue.

7.6.2 Reframing the NICU experience

Parents whose baby has died need to spend time with their deceased baby and they must not be rushed to leave the NICU. This is an area of end of life care that NICUs facilitate well and that nurses are highly skilled in. However, there comes a point for all parents when they feel ready to or want to leave the NICU and this necessitates a separation from their baby. This is a painful and difficult but necessary process. Parents' narrative described 'a revulsion' and fear at having to return to the NICU for

anything once their baby had died. Parents were asked to return to the NICU after the death of their baby for three reasons: to collect the death certificate, to wait to be escorted to the mortuary to see their baby or for a six-week post-bereavement consultant appointment. Parents who were asked to return were newly grieving the death of their baby and were either in the 'Falling In' or 'Sandstorm' area of the NGS. Parents experienced a range of emotions and behaviours, which are presented in Table 7.1. Reframing the NICU experience is a fresh perspective on when the NICU experience ends. NICU exposure should end when the parents leave the NICU after the death of their baby and their baby's body is moved to the mortuary. From that point onwards, the focus should be on facilitating the parents' reintegration back into their community, with their family, friends and community health professionals.

The overwhelming narrative from parents in this study concerning returning to the NICU was that it should be unnecessary and that any request to return was unreasonable. Parents found the return to NICU traumatic, experiencing sights, sounds, smells and interactions with people and places they never wanted to encounter again. This experience potentially increases the intensity of the 'sandstorm' that parents are caught in. Returning to the NICU is not a theme discussed in any of the studies in the literature review in Chapter 2, nevertheless it was prevalent for some parents in this doctoral study.

The experiences of parents having to return to the NICU are common occurrences and health professionals on NICU often view this as a necessary and unfortunate need. This issue was not highlighted in the studies from the literature review in Chapter 2, however it was similarly identified by Snowdon, Brocklehurst, Tasker, Platt, Harvey, Elbourne (2014) in a study of methodology of trials in NICU and how bereaved participants and families should be managed. In Snowdon et al's (2014) study, the six-week follow-up appointment was recognised to be traumatic to parents. There are strategies that could be put into place to reframe this experience after leaving the neonatal unit. There is need to create a new normalised experience of how parents might receive a death certificate and have their six-week consultant appointment in their community settings.

Every effort should be made for the death certificate to be completed expediently. If it is not ready, then the bereavement nurse should visit with the death certificate at the local health centre or in the parent's home (according to their preference). This

opportunity should be used to offer guidance and support with practical matters, undertake any psychological assessments that are needed and give an update to the health visitor. Using this opportunity for the bereavement nurse, parents and health visitor to meet will facilitate a support mechanism close to home, where there is already a duty of care responsibility from the health visitor. Reframing the NICU experience proposes involvement of local community health professionals, the health visitor, alongside the bereavement nurse. Parents' narratives highlighted the lack of health visitor support; facilitating reintegration into the community could be aided by ensuring that the health visitor can understand the parents' position and advocate for them in the future.

Reframing the NICU experience could include changing the venue of the voluntary six-week appointment. The appointment is a national standard of care, it is an appropriate strategy and it is used to discuss any questions or issues parents may have thought about since their baby's death (DH, 2008; Together for Short Lives, 2017). Only a minority of parents in this study wanted to take advantage of the six-week appointment and all had to return to the NICU for this. However, some parents did not find it useful. It is untenable to continue scheduling these appointments on the NICU when parents describe feelings of trauma. Some of the experiences that parents shared included: anxiety, shaking, gaps in their memory, disassociation and mental visuals of when their baby was alive. A bereavement nurse could address many of the issues or questions that parents have; a bereavement service is essential to support parents after their baby has died. There are advantages of having a bereavement nurse undertaking this work for some parents as a trusting relationship is likely to have been formed already with the family. The support strategies proposed for the bereavement nurse will increase the need for resourced posts and this will be considered in Chapter 7.6.3.

Not all follow-up appointments can be facilitated by the bereavement nurse for example, for parents who are awaiting post mortem results or where a coroner's case is ongoing, it may be appropriate to retain a consultant-led appointment. Follow up appointments could be held at the parent's local health centre or an agreed neutral venue. While this is a time resource, measures to ensure parents' emotional and mental health are essential. The purpose of reframing the NICU is to propose a parent-centred approach to bereavement care and prioritises their frail emotional and

mental well-being during the 'sandstorm' of their grief. It locates parents within a supportive community of health professionals with their best interests at the fore.

7.6.3 High quality and timely support

There is consensus across the national guidance, contemporary research evidence and health professional opinion that high quality psychological support at the end of life and through the neonatal parental grief journey is vital (BLISS, 2009; DH, 2008; Lang et al, 2011; Mancini et al, 2013; Robertson et al, 2011; Together for Short Lives, 2017). Nevertheless, whilst high quality psychological support at the end of life is reasonably consistent, bereavement support after death is inconsistent nationally (Robertson et al, 2011). Parents need psychological support at each stage of the NGS. Out of the two NICUs that participants were recruited from, one had an established bereavement team with bereavement support nurses and a bereavement counsellor, the other NICU started to offer part-time bereavement support during the study trajectory. However, across the north-west region of England, there are other level 1-3 NICUs without resourced bereavement support. This is representative of the national picture of a lack of resourcing of bereavement support for parents of deceased neonates (Robertson et al, 2011; Soni et al, 2011). There is vital need for a consistent approach to offering bereavement support across every NICU in the UK, so that parents can expect and receive the same level of care regardless of which NICU their baby died at or where they live.

In conjunction with a need for good quality bereavement support provided by bereavement teams (nurses and counsellors), the timing of support needs consideration. The NGS is used in the next sub-chapter to guide interventions of support and suggested timings (Chapter 7.7). Parents' narrative indicated a diverse range of timings where support need was triggered. However, there were repeating themes about timings of support. First, parents' narratives described confusion and dysfunction in the first few days after the death of their baby. Furthermore, for parents that had been on NICU for some time, there were feelings of abandonment by staff that were no longer part of their life. Second, parents spoke of the significant feelings of isolation that evolved after the funeral of their baby, when all the people around them returned to their lives. Third, there are certain future triggers for support that can be predicted for some parents. Examples of these triggers include: Christmas celebrations for those who celebrate, the first birthday of their deceased

baby and the anniversary of their baby's death. These three areas highlighted are when parents are either 'Falling In' or in the 'Sandstorm' or 'On The Ground' of the NGS.

These timings of support are not new ideas; however, this is the first time research evidence had highlighted from the voice of the parent the importance of timely and supportive neonatal bereavement care. One of the NICUs that parents were recruited from did aim to offer support but parents did not always receive support when they needed it. As previously highlighted, some parents had previously refused support and then waited until they were in crisis before someone sought support on their behalf. There may be a need to seek consent for later contact when parents initially refuse support and 'check-in' how they are coping at predicted trigger points. Not all bereavement support needs to be face-to-face, professionals can offer support over the phone and many of bereavement services that are in place, do use this approach. If parents experience unexpected triggers to their grief where an increase for support arises, an established relationship with their bereavement nurse will facilitate rapid support and return to healthy grief processes.

A national strategic review of how bereavement support is resourced and provided for a consistent approach for all bereaved parents from a NICU is required. The proposal of high quality, timely support from a team of resourced bereavement nurses and counsellors will have an economic impact. This increase in financial resourcing and training of health professionals can be balanced to some degree with the potential reduction in Care Commissioning Group (CCG) budget. A reduction in the CCG budget can potentially be achieved when parents are supported effectively through their grief journeys and consequently have a reduction in somatic symptoms and improved mental health. Introduction of a bereavement nurse framework across the UK has the potential for parents to feel emotionally safe and supported as they leave the NICU without their baby. Parents' perceptions of a member of the NICU team staying involved in their care in the community and being available to support them in the months ahead is something parents in this study wanted to advocate for future parents who will face neonatal bereavement.

Further research is needed in the context of what kind of support parents need, particularly after the death of their baby. For example, how often grief assessments

should be made, which standardised grief assessment tool should be used, what care the bereavement nurse should provide, and when bereavement counselling is indicated.

7.7 Surviving the sandstorm - Using the visualised experience to support parents in practice

This section explores how the Neonatal Grief Sandstorm (NGS) (Figure 6.3) could be used to influence the knowledge and understanding of health professionals, the care and therapeutic interventions for parents during and after the death of their baby. The NGS is not a model or a framework, it is a visual tool through which the findings of this study may be understood and applied to parents in practice and community settings.

The range of models in grief theory that represent the commonalities of the human grief experience, have been outlined in Chapter 1. Some of these models are used in a professional context for practitioners and therapists to understand their client or patient's journey. Visualisation can be a powerful tool for the professional to move from purely understanding the experience, to a position of being able to empathise with the individual. Visual maps and pictures have been used in grief work for decades, for example Stroebe and Schut's (1999) Dual Process Model of Grief aids professionals who are working with the bereaved to understand the swings of emotion and behaviour in grief from evidence to practice (Figure 1, Chapter 1, Section 1.3.4).

Other models that are designed for both professional and client use include the TEAR model related to Worden's tasks of grieving (Worden, 2009). TEAR refers to the way the four parts of Worden's model are represented in the shape of a tear (Appendix V). The TEAR visual tool can be utilised within a therapist - client interaction where they consider the four areas of Worden's tasks of mourning; to accept the reality of the loss, experience the pain, adjust to the new environment and revisit in the future. Using the model, the grieving client can compare and anticipate their own emotions and feelings with TEAR. Another visual tool that is designed to be used with grieving people is the 'The Whirlpool of Grief' (Wilson, 1993), which presents the journey of grief that individuals might experience through a river of life,

waterfall and obstacles of difficulty that would be faced along the river journey (Appendix V). The final visual aid reviewed that is widely used when working with grieving children is the Blobs and the Blog Tree (Wilson and Long, 2018). Using metaphors to visualise and authenticate grief, the experience of the child can be explored. The Blobs and the Blog Tree has been evaluated when used in practice and was found to be useful in exploring the work of grief work with children (Brabant, 2006). Wilson's (1993) whirlpool tool has not been evaluated, however Worden's (2009) tasks of mourning are widely accepted as a theory of understanding grief and mourning.

Reflection Point 7.2 – using visual tools in clinical practice

When I visited families at their homes as a bereavement nurse, I would always go prepared with a 'toolkit' of resources, including some books suitable for the siblings, craft materials if we had an activity planned and I always had some visual tools. I would take the blob tree visual tool to use with children and I would often ask parents to join in with this to encourage grief dialogue between parents and surviving children. For example, "Shall we ask mummy/daddy where they are on the tree today?" We might then have some discussion, for example, "Did you realise mummy was feeling like that today?", and vice versa. Sometimes I would use the 'River of Life' with a parent, talking through the grief experience this represented, if they needed to envisage what might happen next, or felt isolated in their experience. I did not use these visual tools every visit, but I always had them with me in case it seemed appropriate to use them. The NGS visual tool could complement practitioner's existing toolkit of resources.

Visualisations, algorithms, flow charts and diagrams are frequently used in clinical practice as a quick reference tool or to focus a conversation during patient interactions and assessments. The purpose of the NGS is to facilitate a conversation about the key experiences of parents and to help practitioners to consider when support might be timely and when referral to a different service is required. It is envisaged that both bereavement nurses and counsellors could utilise the NGS when supporting bereaved parents. The benefit of using a visual tool or metaphor with a parent in this setting is to facilitate dialogue about a focused topic and Brabant (2006) found that metaphors as visual tools were valuable prompts. This approach could enable parents to identify aspects of the tool that relate to their experience and therefore authenticate their current emotions. In addition, the NGS has the potential to reduce the sense of isolation for some parents by knowing other parents share their experience. From this therapeutic discussion, interventions can be planned, and

support appropriately arranged. It has the potential for parents to be able to think forward to triggers on the horizon and know more about what to expect in their grief journey. The NGS could be part of a toolkit of resources that neonatal bereavement nurses utilise on home visits with families.

The NGS could be used for education purposes with both newly qualified health professionals and those in training so that they can understand the experiences, emotions and grief that parents facing end of life in the NICU encounter. Further, the NGS could be used as part of the training for more experienced health professionals to further develop their knowledge and empathetic understanding of parents' experiences, and develop the skills required to ensure the therapeutic encounter is maximised to meet parents' needs.

The time at which parents need support varies for each individual. However, there are common experiences and time frames that can be anticipated, where there will be a heightened need for support. The exact timing is difficult to predict in terms of days, weeks and months, however there are some key periods along the grief journey that can be anticipated, and contact should be made with parents to ask if support is needed. The key periods for psychological and practical support, arising from the findings in this study and reflecting the NGS are presented in Table 7.1. While it might be assumed that high quality psychological support is available and consistent at the end of life, parents in this study had a range of good, variable and less than optimal support experiences at the end of life.

Period up to end of Year One	NGS	Common symptoms/emotions	Professional Support
End of life	Falling In	Shock, cognitive disruption	Psychological support Practical arrangements Bereavement Nurse
First days after death - end of week one	Falling In	Shock, emptiness, cognitive disruption, difficulty sleeping	Psychological support Advocacy for parents Bereavement Nurse
Days after funeral	Sand storm	Emptiness, useless	Psychological support Bereavement Nurse
Feeling isolated	Sand storm	Strong emotions, not able to talk to anyone, withdrawn	Psychological support Advocacy bereavement nurse Peer support groups Bereavement counselling
Family/friends are particularly worried	Sand storm	Cognitive disorganisation, mental illness, physical ill health	Psychological support Peer support groups Bereavement counselling
Daily functional ability returning for some of the time Socialisation return	On the ground	Back and forth emotions of feeling okay alongside emotions of earlier grief symptoms	Peer support groups Bereavement counselling Psychological support Bereavement nurse
Individual and social triggers (e.g. Christmas and other faith celebrations, friends having babies)	On the ground – moving back to any other part of the sand timer	Return to earlier emotional intensity and disorganisation Psychological distress	Anticipating some triggers with focused psychological support Being contactable for sudden increased need Bereavement nurse Reassessment before discharge from support

Figure 7.1: Key periods for support from 0-12 months

All professionals involved in therapeutic work with a parent approaching end of life with their baby or with a parent bereaved in neonatal period, has the potential to benefit from developing their knowledge. The NGS is generated from experiential

narratives of the parents themselves. This visual has the potential to influence professionals' false preconceptions about what parents in these situations think, feel and experience. The NGS offers an authentic, evidence-based representation of what to expect and how to anticipate grief journeys when involved in neonatal end of life care and bereavement support.

7.8 Summary

This chapter has used theories on loss and grieving to explain and explore the study findings presented in Chapter 6. In addition, the findings have been contextualised in relation to the wider and the established literature. All parents described a vast and deep experience of grief and trying to survive was at times insurmountable. The NGS has been offered as a way facilitate discussions between health professionals and grieving parents to identify their experience and emotional perspective, enabling professionals to make timely referrals as appropriate. In addition, the NGS has the potential to develop professional understanding of parents' experience when their baby is dying and after death.

Chapter 8 – Conclusion

8.1 Introduction

Medical, pharmacological and technological advances in neonatal care have resulted in greater success in resuscitating and sustaining life for a period of time after birth. Unfortunately, some neonatal conditions are not survivable and a significant number of extremely preterm neonates that are successfully resuscitated die of the sequelae of prematurity and technological interventions. High quality palliative and end of life care will always be necessary to ensure that babies die comfortably, with dignity and with their parents holding them through this difficult time. High quality palliative and end of life care includes the psychological care and support of parents and other family members; this care extends into the bereavement period. This doctoral study has prioritised the parents' voices and perspectives within neonatal end of life care, demonstrating the impact of experiences on parents' grief journeys. This chapter presents the key messages from the study findings, and contribution to research on parents' experiences of neonatal death and grief. The chapter will conclude with an outline of the implications of the findings for clinical practice and policy.

8.2 Key messages from the study

This thesis has described and interpreted research data with a population of participants that are difficult to recruit and are rarely represented in the wider theme of palliative care. This phenomenological study presents the voice of parents and their perspective following neonatal bereavement. The four key messages are relevant to health professionals, healthcare strategists, health policy makers, third sector charities, academics and politicians.

First, mothers and fathers appeared to grieve in a reasonably similar way but with different intensity at different times after the death of their baby. However, fathers reported being under pressure to return to life, work and uptake their usual responsibilities soon after their baby's death and were unable to be immersed in grief work for most of their time. This suspension of fathers' grief work has the potential to eventually place fathers in a position of psychological crisis and mental ill health at a later point. Fathers need time to be immersed in grief work, especially in the first few

weeks after the death of their baby. The recent introduction of the Parental Bereavement (Leave and Pay) Act 2018 means that fathers in the future will benefit from some focused time with their partner and family, to be able to be immersed in their grief work. Mothers benefit from being on maternity leave and having time away from work responsibilities with income and focus on their feelings and emotions. Mothers and fathers need individualised assessment for support as they navigate their personal grief journeys.

Second, obstacles to high quality end of life care have the potential to impact significantly on parents' grief journeys and can result in psychological trauma that requires therapy and treatment to recover. The obstacles to high quality care described by parents who participated in this study were a lack of consistency of care from health professionals, confused and upsetting communication differences between different staff members, and untimely and inadequate resuscitation conversations. Parents conveyed the importance of their voice being heard about these issues and that there were solutions and guidance that should have prevented their occurrence.

Third, parents across this study described a reoccurring pattern of being asked to return to the NICU after the death of their baby. This was an overwhelming experience for those parents who returned to the unit; there is a need to reframe the NICU experience with an end point being when the parents leave, and their baby's body goes to the mortuary. The culture of care from this point onwards needs to focus on supporting parents in their grief journey and facilitating reintegration of the family back into the community.

Finally, high quality and timely support is vital for all parents in the UK who experience a neonatal bereavement. It is unsatisfactory for some parents to receive support from a bereavement nurse whilst parents from another neonatal unit do not. A national review of how neonatal bereavement care should be resourced and prioritised is needed to ensure the health and wellbeing of parents who are grieving.

8.3 Contribution to research on parents' experiences of neonatal death and grief

1. This appears to be the first study in the UK to link neonatal end of life care to parents' grief experiences.

This is important because previous studies have either focused solely on grief in a time period after the death of a baby, child or miscarriage; professionals' perceptions of end of life support in the neonatal period; or parents' needs at the end of life. It is crucial for health professionals and policy makers to understand parents' experiences of grief related to end of life care to then be able to attune, develop and resource care and support appropriately. This understanding has the potential to change and improve quality of care at the end of life that then impacts parents' grief experiences and ongoing mental health positively.

2. This appears to be first study of its kind in the UK to use IPA to facilitate the parents' voice on their experiences of and life after a neonatal death.

This is ground-breaking research because this study recruited an ethically difficult and vulnerable population to explore a sensitive and personal subject. The use of IPA as the research method enabled the parents' voice to describe the lived experience of mothers and fathers at the end of life and their journeys into grief. Health professionals make logical assumptions about what this experience is like from their own observations. However, this appears to be the first study where parents are the leaders in guiding the understanding of their own experiences of neonatal death linked to their lived grief experiences.

3. This study provides insight into mothers' and fathers' grief experiences after the death of a baby in a neonatal unit.

Research about neonatal parenting experiences across any aspect of care usually focuses on the mother. Parents (mothers and fathers) experiences are rarely represented in neonatal palliative and end of life research. This is the first study of its kind that describes mothers' and fathers' own perceptions of their grief related to their unique and individual experiences of end of life. This study has made interpretations based on these narratives through data analysis. This study has concluded that mothers and fathers grieve similarly, yet with different intensity

at different times and that life responsibilities and cultural expectations impact on fathers' ability to grieve.

4. A novel finding of this study was the significance of obstacles to high quality neonatal end of life and the negative effect that this had on perceived quality of care and the grief experience.

This study confirmed the wider known and understood phenomenon, that the care given at the end of life can have a detrimental effect on an individual's grief process if it is not of high quality. However, this is new knowledge in the context of neonatal care. When care at the end of life is traumatic or of poor quality, parents' psychological and mental health is affected later as grief evolves. There is potential for this research to significantly and positively impact the practice of both nursing and medical professionals.

5. The development of the Neonatal Grief Sandstorm: a visual tool is the first of its kind in neonatal palliative, end of life and bereavement care.

The parents' narrative and findings elicited a picture of their experiences that evolved into the NGS. This visual tool is aimed to aid health professionals to understand parents' experiences of end of life in NICU and beyond, and to aid senior health professionals to plan and time optimal care and support. The tool is also designed to be used with parents during their grief journeys to identify their experiences and their emotions and feelings; it may also facilitate timely referrals.

8.4 Implications for clinical practice

The study findings have potential to impact on how health professionals care for babies and their parents at the end of life. Specifically care at end of life should ensure the following:

- Every interaction between a health professional and a parent whose baby is at the end of life matters. Conversations about end of life have a significant impact on perceived quality of care but importantly, they have the potential to influence parents' grief experiences positively or negatively. Therefore, each conversation at the end of life should have careful thought to planning and execution and be undertaken by those with the appropriate level of communication skills.

- The importance of health professionals to recognise their own training needs and to prioritise the development of communication skills from foundation level to advanced level is crucial to the wellbeing of parents on a NICU. Health professionals need to prioritise their communication training needs in their professional development review with their line manager.
- Continuity of care needs increased focus for babies at the end of life. This issue is just as relevant across health professional disciplines. Teamwork is crucial alongside continuity of care to ensure that a consistent message about the plan of care is discussed with parents.
- Health professionals need to change the expectations placed on parents to return to the NICU for legal documents and appointments. This is a psychologically traumatic and overwhelming experience for parents and there are solutions that negate the need for parents to return to the NICU. Focus should be placed on facilitating parents' reintegration back into their community.

8.5 Implications for policy

Commissioning and resourcing of neonatal palliative and end of life care is inconsistent across the neonatal units in the UK (Soni et al, 2011). There is inequality of end of life care across different neonatal units according to local resourcing of bereavement support. There is a lack of strategic guidance about how babies and their parents should be cared for at the end of life. The findings from this study have highlighted a need for:

- A resourced bereavement support service for all parents after the death of their baby, which could be located in the neonatal unit. Many neonatal units in the UK do not have a resourced bereavement care team and when parents leave the NICU, they are left with no support. This is an unconscionable situation and untenable considering the impact that a lack of support has on parents' wellbeing.

- A strategic review and task team is needed to attend to and improve the quality of care at the end of life related to a number of areas. These focus areas include: continuity of care guidance placed within the current standards of care from BAPM; resourcing and delivery of advanced communication skills training for health professionals working in NICU; the development of neonatal advanced care plans through a national approach; and a national process for undertaking DNACPR conversations with parents.

8.6 Future research

Research about parents' experiences of neonatal palliative and end of life care is in its infancy. Key priorities for future research include:

- The role and impact of resourced bereavement support services in improving parents' grief experiences needs exploration using an existing validated grief assessment tool.
- The experiences of siblings and grandparents after the death of a brother/sister or grandchild on the neonatal unit needs investigation through two separate studies.
- A study to implement and evaluate the Neonatal Grief Sand Timer as a visual tool in understanding and predicting parents' support needs is needed.

8.7 Final conclusion

The research presented in this thesis revealed that parents have a range of positive and negative experiences on the NICU during their baby's palliative and end of life care. Following death, their grief is a deep and overwhelming experience and parents need a range of supportive options to be able to grieve in a healthy way, without significant detriment to their mental health. The NGS is a novel development and has the potential to support health professionals in their partnership work with parents by being able to identify and authenticate parents' experiences and enable referrals to other professionals where needed.

Bereaved parents should be the drivers for improvement in the quality of neonatal end of life care. This study empowered the parents' voice after bereavement and four themes were developed that have the potential to shape future neonatal end of life and bereavement care. Implications for practice, education, policy development and research have been generated. With neonatal care still being in its infancy compared to many other specialities, there is scope for development that would benefit future parents facing bereavement.

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Appendices

Appendix I	Data Extraction Form
Appendix II	Research ethics committee approval letters
Appendix III	Study Materials
Appendix IV	Recruitment Trackers
Appendix V	Visual Tools for Bereavement Care

Appendix I – Data Extraction Form

Article ID			
Author:		Source:	
Title:			
Study Aim/Hypothesis:			
Study Design: Qualitative: - Grounded Theory - Ethnography - Phenomenology - Other Mixed Methods Quantitative		Sample Strategy: Sample size _____ Purposive Snowball Theoretical Convenience Other _____	
Data Collection Questionnaire Interview Observation Focus groups Other _____		Data Analysis Grounded theory Phenomenology Statistical Content Thematic analysis Other _____	
Criteria (tick or cross as appropriate)			
English Language		After 2002	
Describes parental experience of grief neonatal death			
Describes parental experience of support neonatal death			
Describes impact of neonatal death on parents' lives			
Additional comments/critique:			

Appendix II – Research ethics committee approval letters

Greater Manchester National Research Ethics Service – 14/NW/1007

University of Salford Ethics Application – HSCR13/21



NRES Committee North West - Greater Manchester East

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7820

08 August 2014

Ms Michaela C Barnard
University of Salford
Frederick Road Campus
Salford
M6 6PU

Dear Ms Barnard

Study title:	Parents' experiences and perceptions of their support needs following the death of their baby.
REC reference:	14/NW/1007
IRAS project ID:	112806

Thank you for your response to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Elaine Hutchings, nrescommittee.northwest-gmeast@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study:

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Poster]	3	01 July 2014
Covering letter on headed paper		15 May 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		15 July 2013
Interview schedules or topic guides for participants	4	28 March 2014
IRAS Checklist XML [Checklist_20052014]		20 May 2014
Letters of invitation to participant	2	30 June 2014
Other [Support contacts for participants]	2	04 July 2014
Other [Reply slip]	1	28 March 2014
Participant consent form	5	04 July 2014
Participant information sheet (PIS)	5	04 July 2014
REC Application Form [REC_Form_20052014]		20 May 2014
Referee's report or other scientific critique report		25 July 2013
Response to Request for Further Information		
Summary CV for Chief Investigator (CI) [Michaela Barnard]		23 April 2014
Summary CV for supervisor (student research) [Dr Joanna Smith]		
Summary CV for supervisor (student research) [Prof Caroline Hollins-Martin]		
Protocol	2	21 March 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

14/NW/1007

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



pp

Mr Francis Chan Chair

Email: nrescommittee.northwest-gmeast@nhs.net

Enclosure: "After ethical review – guidance for researchers"

Copy to: Prof. CJ Hollins-Martin

Lynne Webster
Central Manchester University Hospitals NHS Foundation Trust

27 June 2013

Dear Michaela,

RE: ETHICS APPLICATION HSCR13/21 – Parents' experiences and perceptions of support following the death of their baby

Following your responses to the Panel's queries, based on the information you provided, I am pleased to inform you that application HSCR13/21 has now been approved. However, this approval is conditional on us receiving copies of the organisational agreements.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible.

Yours sincerely,

Rachel Shuttleworth

Rachel Shuttleworth
College Support Officer (R&I)

Appendix III – Study Materials

Participant invitation letter

NICU research introduction letter – recruitment site one only

Participant information sheet

Recruitment Poster

Participant reply slip

Informed Consent Form

Interview Guide

Parental support information sheet

Participant invitation letter



Michaela Barnard
Lecturer in Children and
Young People's Nursing
University of Salford
Frederick Road Campus
Salford
M6 6PU
0161 295 3811
m.c.barnard@salford.ac.uk

Dear Parent (s)

We are undertaking research into parents' experiences of during and after the death of a baby, so that more can be learnt about the needs of parents at this difficult time. We appreciate that this will have been and still is a difficult experience for you and your family; however we would like to invite you to take part. We are particularly interested in parents' views of any support they received.

It is hoped this information will help us identify strategies that could be offered to support parents during and after their baby's death in the future. Before you decide if you wish to take part in the study, it is important for you to understand why the study is being done and what it will involve. Please take time to read the enclosed information sheet carefully and discuss it with your family and friends if you wish.

If you would like more information or if there is anything that is not clear, please contact:

Michaela Barnard, School of Nursing, Midwifery and Social Work, University of Salford

Tel: 0161 295 3811 e-mail: m.c.barnard@salford.ac.uk

Yours sincerely

Michaela Barnard

NICU research introduction letter – recruitment site one only

(Trust letterhead and names have been removed, replaced with X)

Dear

The nursing and medical staff on the Neonatal Intensive Care Unit at X are constantly seeking to improve the care which they give to families who experience bereavement. We have been asked by Michaela Barnard, Lecturer in Children and Young People's Nursing at University of Salford to help with her study exploring Parents' experiences and perceptions of their support needs during and following the death of their baby.

Our only role in the research is to identify potential participants and to send out an information pack about the research to those parents. Your details will remain confidential and the researcher will only have your contact details if you decide you would like to be involved and contact her after you have received the information pack.

We are aware this may be difficult for you and would therefore be very grateful if you feel able to take part. The Neonatal Bereavement Team will not be informed whether you decide to participate or not and your care will not be affected in any way.

We do hope this letter has not upset you. If you would like any further support or information, or do **not** wish to receive the information pack, please use the contact details above to email us or leave your name and a message on our answer phone.

You will receive the information pack in about two weeks if we do not hear from you. Thank you for your cooperation.

Yours sincerely,

Will my taking part in this study be kept confidential?

All information collected about you and your baby during the course of the study will be kept strictly confidential.

What can you do if you are not satisfied with the process?

If you have a complaint about your involvement in this study you can contact Alison Brettle, Programme Leader for PhD.

Tel: 0161 295 0447 e-mail: a.brettle@salford.ac.uk

What will happen to the results of the study?

Key findings will be presented at neonatal team meetings. The full results of the study will be written up as a thesis by Michaela as part of her post graduate study. This may result in publications in a healthcare journal or presentations at a healthcare conference. You or your baby will not be identified in any report or publication. Michaela will provide a newsletter summarising the results of the study for participants who wish to receive it.

What should I do if I wish to take part in this study?

If you wish to participate please telephone or email Michaela once you have read the information provided. Michaela will then contact you to discuss the study in more detail. She will then provide you with a consent form to complete and arrange a convenient day and time to interview you.

Thank you for your time to consider taking part in this study.

Participant information sheet**Parents' experiences and perceptions of their support needs following the death of their baby**

You are being invited to take part in a study that is exploring parents' experiences during and following the death of their baby. In particular, we are interested in parents' views of the support they received during and following their baby's death. It is hoped this information will help us identify strategies that could be offered to support parents in the future. Before you decide if you wish to take part in the study, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with your family and friends if you wish. If you would like more information or if there is anything that is not clear, please contact:

Michaela Barnard, School of Nursing, Midwifery and Social Work, University of Salford

Tel: 0161 295 3811 e-mail: m.c.barnard@salford.ac.uk

Who are we?

The people involved in the study are:

Michaela Barnard, who worked on a Neonatal Intensive Care for 15 years and worked for seven years as a Bereavement Support Sister. She is undertaking this research as part of her PhD. Professor CJ Hollins-Martin and Dr Joanna Smith, who are researchers and lecturers at the University of Salford/Huddersfield are supervising the study.

What is the purpose of the study?

The purpose of the study is to help us to understand the kind of experiences parents have during and following the death of their baby and what support is helpful once they leave the hospital. Any individual complaints about care should be directed to the hospital where your baby was cared for.

Why have I been chosen?

You have been chosen because your experiences are relevant to the study. We are expecting to have 15-20 parents participating in the study.

Are there any benefits from taking part?

You will not benefit directly by taking part, but the findings of this study may contribute to improving the care and support provided to parents around the time of death of their baby and once they leave the hospital.

Do I have to take part?

It is up to you to decide whether or not to take part in this study. If you do not wish to take part we will not contact you again about this study. The standard of support/care you may be currently receiving

will not be affected in any way. If you decide to take part you will be asked to sign a consent form and given a copy of the form to keep. You are free to withdraw at any time and without giving a reason, even if you have signed the consent form. A decision to withdraw at any time will not affect the standard of any care/support you receive, now or in the future.

What will happen if you decide to take part in the study?

If you wish to participate in the interview, you will be asked to provide a contact telephone number and Michaela will contact you to discuss the study. You will be invited to participate in an interview with Michaela. The interview will focus on your experiences and views at the time of death of your baby and any support you received after you left the hospital. The interview will last approximately 90 minutes and take place in a venue of your choice. If you wish to be interviewed at the university, travel costs will be reimbursed. If both parents wish to participate, you can choose to be interviewed separately or together. The interview will be recorded if participants are agreeable to this. You will also be invited to a follow-up meeting when all the interviews have been undertaken. This is an optional meeting and would be expected to last one hour. Other parents who have participated in the study will also be invited. The meeting will give you the opportunity to discuss the key issues that have been identified from the interviews.

Parents' experiences and perceptions of their support needs following the death of their baby



Researchers at the University of Salford are undertaking a study exploring parents' experiences and the support they received during and following their baby's death.

This information will help us identify strategies that could be offered to support parents during and after their baby's death in the future. If you would like more information or wish to take part in the study, please contact:

Michaela Barnard, School of Nursing, Midwifery, Social Work and Social Policy, University of Salford

Tel: 0161 295 3811

e-mail: m.c.barnard@salford.ac.uk

Participant Reply Slip (A5 size)

If you would like further information about the study or would like to participate, please either email Michaela on m.c.barnard@salford.ac.uk or leave a message on 0161 295 3811.

Alternatively, please fill in your contact details and use the stamped addressed envelope and Michaela will get in touch with you.

Name: _____

Address (optional): _____

Telephone: _____

Informed Consent Form

Parents' experiences and perceptions of their support needs following the death of their baby

Participant Consent Form

Participant's Name

Please tick and initial each box

I confirm that I have read the information sheet about the study. ☐

I have had the opportunity to ask questions. ☐

I understand the purpose of the study. ☐

I understand, and accept, that if I take part in the study I will not gain any direct, personal benefit from it. ☐

I understand that all information collected in the study will be held in confidence and that verbal quotes will be anonymised. If the work is presented or published, all personal details will be removed. ☐

I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Salford, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

I confirm that I will be taking part in this study of my own free will, and I understand that I may withdraw from it, at any time and for any reason, without affecting legal rights. ☐

- a. I agree to take part in the study that involves audio-recording the interview between myself and Michaela Barnard. ☐
- b. I would be willing to be part of a group meeting where Michaela Barnard will feedback the key findings that have arisen from the interview study. ☐

Participant's Signature

Date

Researcher's Signature

Date

Interview Guide

Interview Schedule

Parents' experiences and perceptions of support needs following the death of their baby

Introduction

Purpose, confidentiality, permission to record/take notes.

Warm-up - Could you tell me about yourself and your family?

Interview Guide

1. Could you tell me about **(name)**?
2. Could you describe your experience when **(name)** was in hospital?
3. Could you explain how things have been for you since you left the hospital?

Prompts
2a. What helped you during this time?
2b. Did anything add to your difficulties during this time?
2c. On discharge were you offered any ongoing support?

Prompts
3a. What has helped you?
3b. What have you struggled with?
3c. Have you been in touch with any support groups?
3d. Who do you talk to on a bad day?

Closure

4. What would you recommend health care professionals could do to support a family in a similar situation?

We are nearing the close of the interview, would you be willing to answer some general questions about you? Age, ethnic group, your occupation and partner's occupation (if applicable).

Reminder – Discuss support strategies after the interview

Parent support information



Thank you for taking part in this important study.

We recognise that talking about your experiences concerning the death of your baby is difficult. These conversations can sometimes highlight the need for some further support. Below is a list of resources, contact telephone numbers and local support groups. Please feel free to make contact with one of the below organisations and/or if you wish to, speak to your GP or Health Visitor.

Stillbirth and Neonatal Death Society (SANDS) Support Groups

General contact	Phone: 020 7436 5881	Email: helpline@uk-sands.org
Manchester SANDS	Phone: 0161 881 7790	
Oldham SANDS	Phone: 07906 438001	Website: http://www.oldhamsands.co.uk
Stockport SANDS	Please call the Sands helpline on 020 7436 5881 for details on this group or email helpline@uk-sands.org .	

Salford SANDS	Please call the Sands helpline on 020 7436 5881 for details on this group or email helpline@uk-sands.org .	
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Wigan SANDS	Phone: 07521 429972	Website: www.wigansands.moonfruit.com
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Huddersfield SANDS	Phone: 07867 912987	Email: huddersfieldsands@yahoo.co.uk
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The Compassionate Friends Supporting bereaved parents and their families after the death of a child. Phone line 0845 123 2304 Daily 10am-4pm, 7pm-10pm. www.tcf.org.uk

Child Bereavement Charity (CBC) Supporting bereaved families after the death of a child.

Phone line 0800 02 888 40 Mon-Fri, 9am-5pm. www.childbereavementuk.org Email support: support@childbereavementuk.org

Cheshire (Runcorn) CBC Family Support Group Phone: 01928 577164 Email: barry.lyonette@childbereavementuk.org

The Child Death Helpline For anyone affected by the death of a child Freephone landline: 0800 282 986. Freephone all mobiles: 0808 800 6019 Mon-Fri 10am-1pm, every evening 7pm-10pm.

For Muslim families exclusively:

The Children of Jannah www.ChildrenofJannah.com Email support@ChildrenofJannah.com Support and Information Line 0161 480 5156 (Tues-Fri 10am-4pm)

Appendix IV – Recruitment Trackers

Tracker for Recruitment Centre One

Tracker for Recruitment Centre Two

Recruitment Centre 1 Parents' experiences and perceptions of support following the death of their baby REC Ref: 14/NW/1007

Name and Pack No	Date of Death	Incl. Criteria	Excl. Criteria and Reason	Date Study Pack Sent	Comments

Recruitment Centre 2 Parents' experiences and perceptions of support following the death of their baby REC Ref: 14/NW/1007

Name and Pack No	DOD	Incl. Criteria	Excl. Criteria and Reason	Date NICU Audit Sent	Date Intro Letter Sent	Date Study Pack Sent	Comments

Appendix V – Visual Tools for Bereavement Care

TEAR model

The Whirlpool of Grief



the tasks of grief

T = To accept the reality of
the loss

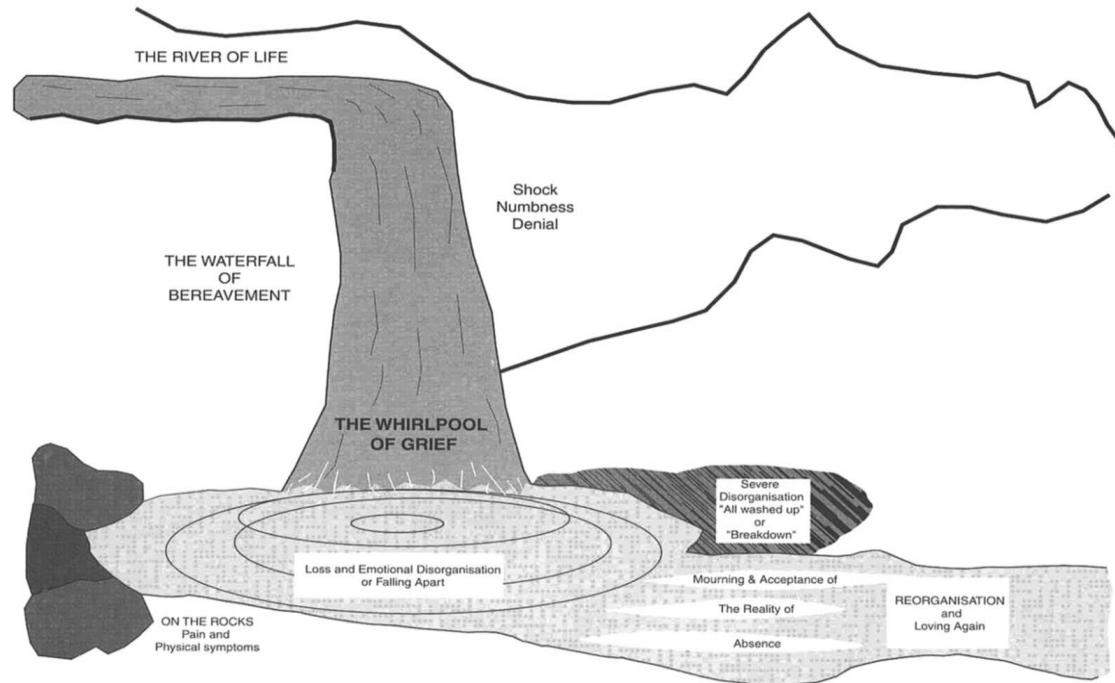
E = Experience the pain of the loss

A = Adjust to the new environment
without the lost person

R = Reinvest in the new
reality

Based on Worden (2009)

THE WHIRLPOOL OF GRIEF



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